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Illness Representations, Treatment Beliefs and  
the Relationship to Self-Care in  
Heart Failure

by

Julie MacInnes

Canterbury Christ Church University

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# ABSTRACT

## Purpose

The purpose of this study was to explore the beliefs people with heart failure hold about their illness and its treatment and to determine any relationships between these beliefs and self-care using the Common Sense Model (CSM) of illness cognitions and behaviour as the theoretical framework (Leventhal et al, 1980).

## Methods

Using a mixed methodology (Creswell and Plano Clark, 2007), findings from patient interviews were used to adapt the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al, 2002) and the Beliefs about Medicines Questionnaire (BMQ) (Horne et al, 1999) in order to make them illness-specific. A questionnaire assessing self-care was developed based on the European Heart Failure Self-care Behaviour Scale (EHFScBS) (Jaarsma et al, 2003), the interview findings and a nominal group technique with specialist heart failure nurses. These questionnaires were used to determine beliefs and the relationship to behaviour in a cross-sectional survey of 169 patients with heart failure.

## Results

A number of statistically significant correlations were found between beliefs and self-care. Most notably, perceived medication knowledge ( $r = 0.51$ ,  $p \leq 0.01$ ), beliefs about the necessity of medication ( $r = 0.45$ ,  $p \leq 0.01$ ) and illness coherence ( $r = 0.39$ ,  $p \leq 0.01$ ). Multiple regression analysis revealed that 46% of the variance in self-care could be explained by illness representations and treatment beliefs (Adj.  $R^2 = 0.46$ ,  $F = 9.93$ ,  $p = 0.00$ ). Three factors were significant predictors of self-care - medication knowledge ( $\beta = 0.319$ ,  $p = 0.003$ ), a belief in the illness having serious consequences ( $\beta = 0.258$ ,  $p = 0.008$ ) and the impact of medication use on lifestyle ( $\beta = -0.231$ ,  $p = 0.03$ ).

## Discussion

The exploration of illness representations revealed a realistic picture of heart failure with a cluster of beliefs around a chronic illness with serious consequences and a high number of symptoms. There was a strong belief in the necessity of medication but for some, medication use had a negative impact on daily life. Patients were confident in their knowledge of medication but this was reduced when family members took control of medication management. A number of beliefs were predictive of self-care, suggesting that interventions designed to maximise these beliefs and correct any misconceptions may enhance self-care and potentially improve clinical outcomes in this population.

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*Be near me when my light is low,  
When the blood creeps and the nerves prick  
And tingle; and the heart is sick,  
And all the wheels of Being slow.*

Alfred, Lord Tennyson (1809-1892)

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**WORD COUNT**      88,156

## LIST OF ABBREVIATIONS

ACEI	Angiotensin Converting Enzyme Inhibitor
AHA	American Heart Association
BHF	British Heart Foundation
BMQ	Beliefs about Medicines Questionnaire
BNP	B -Type Natriuretic Peptide
CAQDAS	Computer-Assisted Qualitative Data Analysis
CCCU	Canterbury Christ Church University
CHD	Coronary Heart Disease
CSM	Common Sense Model
DH	Department of Health
EHFScBS	European Heart Failure Self-care Behaviour Scale
EPP	Expert Patient Programme
GP	General Practitioner
HF	Heart Failure
HFN	Heart Failure Nurse
HRQoL	Health-Related Quality of Life
ICD	Internal Cardioverter Defibrillator
IPQ	Illness Perception Questionnaire
IPQ-R (HF)	Revised Illness Perception Questionnaire, Heart Failure
IPQ-R	Revised Illness Perception Questionnaire
LAYHFQ	Looking After Yourself with Heart Failure Questionnaire
MEMS	Medication Event Monitoring System
MI	Myocardial Infarction
MUHFQ	Medication Use in Heart Failure Questionnaire
NTproBNP	N-terminal pro-B-type natriuretic peptide
NGT	Nominal Group Technique
NICE	National Institute of Clinical Excellence
NMC	Nursing and Midwifery Council
NREC	National Research Ethics Committee
NSAIDs	Non-Steroidal Anti-Inflammatory Drugs
NYHA	New York Heart Association
PCA	Principal Components Analysis
PCT	Primary Care Trust
SCHFI	Self-Care in Heart Failure Index
SDQ	Socio-Demographic Questionnaire
SIBHFT	Survey of Beliefs in Heart Failure Tool
WHO	World Health Organisation

## **CHAPTER ONE: INTRODUCTION**

Heart failure is a collection of symptoms and signs that suggest impairment of the heart as a pump (National Institute of Clinical Health and Excellence (NICE), 2010). It is a prevalent condition affecting approximately 177,000 people in the United Kingdom (UK) (Scarborough et al, 2010). Although it is considered a chronic or long-term condition, those affected suffer frequent acute episodes and experience a high number of hospital admissions. The Department of Health (DH, 2000a) state that this pattern of illness is largely due to uncontrolled symptoms as a result of non-adherence to medication and lifestyle advice. Consequently, individuals with heart failure need to develop and maintain effective strategies and behaviours to care for themselves and manage their illness (NICE, 2003). This is supported by government policy, which has emphasised self-care as a key principle in the management of long-term conditions such as heart failure (DH, 2005a).

Enabling effective self-care is not simply a matter of enhanced patient education. Jaarsma et al (2000a) found that despite intensive education and support, patients with heart failure did not consistently demonstrate effective self-care. Many factors are thought to be involved in changing behaviour including demographic, social and psychological influences. Self-regulatory theory has provided a useful structure for advancing our understanding of how individuals make sense of their illness and respond in terms of behaviour (Leventhal et al, 1980).

This chapter begins by explaining the significance of the topic and defines the key terms of 'heart failure' and 'self-care', as used in this thesis. It sets the context of the research in relation to the main areas of literature. The origins of the idea for the study and my background as the researcher are reflected upon. The setting for the research is discussed and an overview of the research design is presented including a statement of the research aims and objectives. The chapter concludes by outlining the content and structure of subsequent chapters.

### **1.1 THE SIGNIFICANCE OF THE TOPIC, DEFINITION OF TERMS AND THE CONTEXT OF THE RESEARCH**

Heart failure has a significant impact on individuals, their families and on healthcare provision and resources. The disease accounts for approximately 5% of all emergency admissions to general medical or elderly care hospital beds in the UK and readmissions are common with one in four patients returning to hospital within three months (Cleland et al, 2003). The number of in-patient episodes in 2008/9 has been recorded as in excess of

100,000 (Scarborough, 2010). Annual mortality ranges from 10-50% depending on initial illness severity (Petersen et al, 2002).

The term 'heart failure' is defined in this thesis as:

*'A complex clinical syndrome of symptoms and signs that suggest impairment of the heart as a pump supporting physiological circulation'* (NICE, 2010, p.19)

The justification for the use of the term 'heart failure', as opposed to other commonly used clinical terms, and the decision to apply this definition is discussed in section 2.1.1.

There is now an established body of evidence for heart failure prevention, treatment and care. This is most notably reflected in the National Service Framework (NSF) for Coronary Heart Disease (CHD) (DH, 2000a) and Chronic Heart Failure: National Clinical Guideline for Diagnosis and Management in Primary and Secondary Care (NICE, 2010). Whilst this most recent publication emphasises the medical management of heart failure, lifestyle behaviours such as a reduced salt diet, have also been recommended (NICE, 2003). Supporting patients and their families is a key recommendation for practice and the management of heart failure is seen as a shared responsibility between the patient, family and health and social care professionals.

Shared responsibility for care and the concept of self-care has been established government policy since 2000 when self-care was first introduced in the NHS Plan as '*a key building block for a patient-centered health service*' (DH, 2000b, p.3). Since then, a number of key policy documents have driven the self-care agenda. These are discussed in detail in section 2.3.1. 'Self-care' in long-term conditions is defined in this thesis as:

*'The activities that enable people to deal with the impact of a long-term condition on their daily lives, dealing with the emotional changes, adherence to treatment regimes, and maintaining those things that are important to them – work, socialising, family'* (DH, 2006a, p.2)

Dickson et al (2006) conceptualise self-care in heart failure as a decision making process comprised of two elements - self-care maintenance and self-care management strategies. Self-care maintenance includes those actions believed to maintain a maximum level of health and functioning through adherence to medication regimes and recommended lifestyle advice such as reduced fluid intake and taking regular exercise. Self-care management includes recognising and monitoring symptoms such as fluid retention, through, for example, regular weighing and responding when symptoms worsen by seeking appropriate help.

Effective self-care is, therefore, important in terms of clinical management and government policy. However, it has been suggested that self-care in this population is poor (Leventhal et al, 2005; Artinian et al, 2002). A large number of studies have attempted to explain this by identifying factors that affect self-care, for example, Dunbar et al, (2005); Chriss et al, (2004) and Jaarsma et al, (2000b). Only a few studies have considered the influence of illness and treatment beliefs on self-care in heart failure.

The common sense model (CSM) of illness cognitions and behaviour (Leventhal et al, 1980) has provided a framework within which behavioural responses to a number of illnesses have been explained and predicted (Hagger and Orbell, 2003). Within this model, illness cognitions or representations inform the development of coping strategies or behaviours. Illness representations are defined as '*an organised set of beliefs regarding illness*' (Cameron and Moss-Morris, 2004, p.85). Horne (1997) proposed an extended CSM which incorporated beliefs about treatment, specifically the necessity of medication and concerns about its use.

Using the CSM, Horowitz et al (2004) in a qualitative study, described the relationship between illness representations and actions in heart failure as '*a story of maladies, misconceptions and mishaps*' (p.631). Albert and Zellar (2007) similarly found inaccurate illness beliefs which had a negative impact on self-care. Morgan (2008) found mostly accurate illness representations in a Republic of Ireland population, with beliefs significantly predicting self-care. In contrast, Voelmeck (2006) found no significant correlations between illness representations and self-care. No published studies have been identified which consider the relationship between illness representations, treatment beliefs and self-care in a UK, heart failure population. This study attempts to do so.

In summary, this study is important in that it addresses a significant clinical problem. Heart failure is a prevalent disease associated with poor clinical outcomes. Optimal management is dependent upon effective self-care which some authors suggest is limited. It is proposed here, that a greater understanding of the beliefs people hold about their illness and its treatment may help to explain and predict self-care in heart failure. The CSM model (Leventhal et al, 1980) has been useful in predicting illness behaviour in a number of illness groups and provides the theoretical framework for this research.

This study should lead to a greater understanding of how patients make sense of their illness and respond in terms of adherence to medication and other self-care behaviours. It is envisaged that this may enable service providers, such as general practitioners (GPs), practice nurses, community matrons, specialist heart failure nurses (HFNs) and health



psychologists, for example, to develop targeted interventions aimed at promoting more effective self-care routines by addressing any misconceptions about the illness and its treatment. It is known that interventions which address illness representations can be effective in changing illness behaviour and improving outcomes for patients (Petrie et al, 2002). It is hoped that this research may ultimately lead to improved outcomes for heart failure patients as measured by hospital admission rates, improved symptom control or prognosis, for example.

Literature has primarily been drawn from the disciplines of health and social care policy and practice, health psychology and the sociology of health and illness. Four main topics have been explored in the literature namely, the nature and management of heart failure from a predominantly biomedical viewpoint, lay beliefs and social and psychological perspectives of health, illness and treatment, self-care within a health and social care policy framework and the factors believed to influence self-care in heart failure, including illness and treatment beliefs. The measurement of illness representations, treatment beliefs and self-care is also discussed.

## **1.2 ORIGINS OF THE STUDY**

As a staff nurse in a coronary care unit with a remit for health education, I was frequently surprised that, despite suffering chronic or acute, life-threatening cardiac illnesses, many patients did not seem to alter their lifestyle as recommended by nursing and medical staff. Their willingness or ability to make recommended lifestyle changes, even after health education, seemed to be limited. Patients would often recite risk factors for heart disease but did not seem to personally identify with them. It seemed to me that they could tell me why other people developed heart disease but that this was not the case for them. Over time and through further study, I realised that changing behaviour is not simply a matter of knowing all the facts – it is much more complex than that, involving factors such as motivation, self-efficacy and social support, for example.

Later, as a lecturer in cardiac nursing, I was recommended to read a book entitled 'Perceptions of Health and Illness' edited by Keith Petrie and John Weinman (1997). In this book, the role of illness beliefs in changing behaviour was discussed and I felt that clues to why some people changed their behaviour in response to illness whilst others did not might be found in this area of study.

In studying for an MSc. in Interprofessional Health and Social Care, I elected to do a dissertation on the illness representations of women following acute myocardial infarction (MI) as I wanted to apply my newfound interest in health psychology, specifically illness

representations, to this under-represented population. The experience of doing this small scale, qualitative study encouraged me to develop this area of interest further in a PhD. The increasing focus on heart failure and self-care within cardiac care practice expanded my area of interest. As well as exploring illness representations qualitatively, it also seemed to be important to determine possible relationships between beliefs and behaviour through quantitative methods. Despite a lack of formal training in health psychology and quantitative methods, my experience as a cardiac nurse coupled with my limited experience of research in illness representations, motivated me to pursue this area of study. This led to the development of the aims and objectives of the research, stated below.

### **1.3 AIMS AND OBJECTIVES**

The aims of the research were:

1. To explore illness representations, treatment beliefs and self-care in heart failure.
2. To determine relationships between illness representations, treatment beliefs and self-care in heart failure.

The objectives were:

1. To conduct semi-structured interviews with a sample of heart failure patients to explore illness representations, treatment beliefs and self-care.
2. To adapt or develop as necessary, questionnaires measuring illness representations, treatment beliefs, socio-demographic factors and self-care in heart failure.
3. To use these questionnaires to determine relationships between these variables in a cross-sectional survey.

### **1.4 THE RESEARCH SETTING AND AN OVERVIEW OF THE RESEARCH DESIGN**

The study was conducted in three NHS Primary Care Trusts (PCTs) in the South East of England, in a sample of community-based patients with heart failure. These sites were selected on the basis of convenience as they were local and easily accessible. Community heart failure patients, rather than those in acute services, were chosen as these patients were living with their illness on a day-to-day basis, reflecting routine self-care rather than during brief episodes of acute exacerbation of symptoms. Ethically, it also seemed to be inappropriate to ask patients to participate in research when they were acutely unwell and physically and emotionally more vulnerable.

A mixed methods research design was chosen using an exploratory, instrument development model as defined by Creswell and Plano Clark (2007). An exploratory model is described as occurring in two phases, where the results of the first, qualitative method

inform the second, quantitative method. The central premise of this design is that an initial exploration of the topic is necessary. In the instrument development model, phase one is the collection of qualitative data to explore a phenomenon which builds to a quantitative phase by developing instruments which are then used to collect quantitative data.

This research, therefore, was conducted in two sequential phases. Phase one explored illness representations, treatment beliefs and self-care in heart failure from a patient perspective, using semi-structured interviews. Based on the findings of these interviews and using an expert group of HFNs, three questionnaires were adapted, largely from pre-existing instruments, to measure illness representations, treatment beliefs and self-care. A questionnaire measuring socio-demographic characteristics was also developed. These four questionnaires were then used to collect quantitative data in phase two of the research, where relationships between illness representations, treatment beliefs, socio-demographic factors and self-care were assessed in a cross-sectional survey.

This research design was chosen as it was felt that illness representations, treatment beliefs and self-care had not been adequately explored in a UK population of heart failure patients. Although instruments have been developed to assess illness representations and treatment beliefs, most notably the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al, 2002) and the Beliefs about Medication Questionnaire (BMQ) (Horne et al, 1999), these are not illness-specific. Albert and Zeller (2007) developed the Survey of Illness Beliefs in Heart Failure Tool (SIBHFT) based on the CSM but measuring the accuracy and certainty of illness beliefs rather than the nature of illness beliefs *per se*. Questionnaires measuring self-care in heart failure have been developed, most notably the European Heart Failure Self-care Behaviour Scale (EHFScBS) (Jaarsma et al, 2003), although it has been argued that its use should be further explored in a UK population (Shuldham et al, 2007). These instruments are discussed in Chapter two.

## **1.5 STRUCTURE OF THE THESIS**

This thesis is organised into eight chapters according to the main arguments and processes of the research. Chapter two reviews the literature pertinent to the topic and provides the context for the study. Chapter three discusses the methodology and locates the research within the philosophical paradigm of pragmatism. The research design is identified as mixed methods and an overview of the methods is provided. Chapter four discusses the methods and results of phase one, the qualitative interviews. Chapter five describes the pilot study and the adaptation and testing of the questionnaires to be used in phase two, the quantitative survey. Chapter six discusses the methods and results of phase two. Chapter seven integrates the findings of the qualitative and quantitative

phases in an overall discussion according to the aims of the study. The strengths and limitations of the methodology are discussed and the implications for health and social care practice are considered before suggesting opportunities for future research. Chapter eight summarises the study and concludes by examining the extent to which the aims of the research have been met.

## **CHAPTER TWO: LITERATURE REVIEW**

The previous chapter has given an overview of the design and aims and objectives of the research. The care of patients with heart failure has been identified as a significant clinical issue with self-care seen as an important aspect of management. This chapter explores, in more detail, the literature relating to key areas of the study, namely, the nature and management of heart failure from a biomedical viewpoint, lay beliefs and social and psychological perspectives of health, illness and treatment, self-care within a health and social care policy framework and factors known to influence self-care in heart failure including illness and treatment beliefs.

In accessing the literature, the electronic databases of ASSIA, British Nursing Index, CINAHL, Cochrane, Medline, PsychINFO and ScienceDirect were searched using key terms of 'heart failure', 'lay beliefs', 'Illness beliefs' 'illness perceptions', 'illness representations', 'treatment beliefs', 'self-care' and 'self-management'. These were used singularly and in combination. No limits were imposed in terms of publication dates in order to source all relevant articles. Leading authors were searched for by name, for example, 'Leventhal', 'Weinman', 'Horne', 'Jaarsma' and 'Riegel'. Key journals were also selected individually and searched, for example, the British Journal of Cardiac Nursing, British Journal of Health Psychology, European Journal of Cardiovascular Nursing, Psychology and Health, and the Sociology of Health and Illness. The abstracts of accessed articles were scrutinised for relevance to the topic and full text copies were obtained where appropriate. The reference lists of sourced articles were also checked for other relevant literature. The websites of the DH, NICE, the British Heart Foundation (BHF), local NHS Trusts, the British Society of Cardiology (BSC), the European Society of Cardiology (ESC), the American Heart Association (AHA), the British Psychological Society (BPS) and the European Psychological Society (EPS) were also accessed and searched. Relevant conference proceedings and theses or 'grey literature' (Polit and Hungler, 2001) were accessed. Research supervisors and colleagues also recommended specific articles, topics and authors. ZETOC alerts were set up by e-mail so that newly published work by key authors and in key topic areas could be identified. In this way the literature was continuously updated. No new literature was included after December 2010 when the thesis was in the final stages of completion.

### **2.1 THE NATURE AND MANAGEMENT OF HEART FAILURE**

This section begins by defining the term heart failure and explores the difficulties this presents. The importance of heart failure in epidemiological terms, its presentation and

clinical management will then be discussed according to a predominantly biomedical model. The purpose of this is not only to justify the selection of heart failure as an important topic and the focus of this thesis but also to set out the dominant, established view of the disease against which the individual experience of the illness can be compared. By integrating professional and lay perspectives of heart failure in this way, it is hoped that a more inclusive representation of the illness emerges.

### **2.1.1 Defining heart failure**

Defining what the term heart failure means is problematic not least because it is thought of as an umbrella term for a number of cardiac muscle abnormalities or cardiomyopathies (Nicholson, 2007). As stated in the previous chapter, the definition of heart failure by NICE (2010) has been adopted in this thesis as it is current and authoritative whilst being broad enough to include the many different forms of the condition:

*‘A complex clinical syndrome of symptoms and signs that suggest impairment of the heart as a pump supporting physiological circulation’* (NICE, 2010, p.19)

Describing exactly *how* the heart is failing or identifying the specific cardiomyopathy can be useful in determining the cause of the illness and guiding clinical management. The World Health Organisation (WHO) brought together a list of the main cardiomyopathies which covered the majority of cases of heart failure. The American Heart Association (AHA) has since revised this list which is now used to describe the various types of heart failure in the UK, Europe and the US (Maron et al, 2006) (Table 2.1).

According to the AHA (Maron et al, 2006), cardiomyopathies are classified as primary or secondary and can be characterised as structural or functional pathological changes. Terms such as ‘dilated’ or ‘hypertrophic’ cardiomyopathy define the structural changes that occur within the myocardium or heart muscle. Functional changes in cardiac performance such as ‘systolic’ or ‘diastolic’ failure can also be described whilst ‘left’ and ‘right’ ventricular failure specifies the location of the disorder. In addition, the duration of the abnormality can be described with the terms ‘acute’ or ‘chronic’ widely used. Most recently, NICE (2010) divides heart failure into Left Ventricular Systolic Dysfunction (LVSD), which accounts for approximately 50% of all cases of heart failure in the UK, and Heart Failure with Preserved Ejection Fraction (HF-PEF), based on echocardiographic findings.

Heart failure is the preferred overarching clinical term in the UK (DH, 2000a), although other terms such ‘cardiac failure’, ‘congestive cardiac failure’ (CCF) and ‘left ventricular failure’ (LVF) are still prevalent in the literature and used by clinicians. As a result, the

patient may be presented with an array of labels describing a complex condition which may make understanding the illness difficult for them and their families.

**Table 2.1      The American Heart Association (AHA) Classification of Cardiomyopathies**

<b>Primary Cardiomyopathies</b>	
Genetics	<ul style="list-style-type: none"> <li>• Hypertrophic Cardiomyopathy</li> <li>• Arrhythmogenic Right Ventricular Dysplasia (ARVD)</li> <li>• Conduction System Disease (Lenerge Disease)</li> <li>• Ion Channel Diseases (e.g Brugada Syndrome)</li> </ul>
Mixed (Genetic and Non-genetic)	<ul style="list-style-type: none"> <li>• Dilated Cardiomyopathy</li> <li>• Primary Restrictive Non-Hypertrophied Cardiomyopathy</li> </ul>
Acquired	<ul style="list-style-type: none"> <li>• Myocarditis</li> <li>• Stress (Tako-Tsubo) Cardiomyopathy</li> <li>• Peripartum Cardiomyopathy</li> <li>• Arrhythmia Induced Cardiomyopathy</li> <li>• Alcoholic Cardiomyopathy</li> </ul>
<b>Secondary Cardiomyopathies</b>	
Infiltrative	<ul style="list-style-type: none"> <li>• Amyloidosis</li> <li>• Gaucher Disease</li> <li>• Hurler's Disease, Hunter's Disease</li> </ul>
Storage	<ul style="list-style-type: none"> <li>• Haemochromatosis</li> <li>• Fabry's Disease</li> <li>• Glycogen Storage Disease</li> <li>• Nieman-Pick Disease</li> </ul>
Toxicity	<ul style="list-style-type: none"> <li>• Drugs, Chemicals</li> <li>• Heavy Metals</li> </ul>
Endomyocardial	<ul style="list-style-type: none"> <li>• Endomyocardial Fibrosis</li> <li>• Loeffler's Endocarditis</li> </ul>
Inflammatory	<ul style="list-style-type: none"> <li>• Sarcoidosis</li> </ul>
Endocrine	<ul style="list-style-type: none"> <li>• Diabetes Mellitus</li> <li>• Hyper/Hypothyroidism, Hyperparathyroidism</li> <li>• Pheochromocytoma</li> <li>• Acromegaly</li> </ul>
Cardiofacial	<ul style="list-style-type: none"> <li>• Noonan Syndrome</li> <li>• Lentiginosis</li> </ul>
Neuromuscular/Neurological	<ul style="list-style-type: none"> <li>• Friedreich's Ataxia</li> <li>• Duchenne-Becker Muscular Dystrophy</li> <li>• Myotonic Dystrophy</li> </ul>
Nutritional Deficiencies	<ul style="list-style-type: none"> <li>• Beriberi, Scurvy</li> <li>• Pellagra</li> <li>• Selenium</li> <li>• Carnitine</li> </ul>
Autoimmune/Collagen	<ul style="list-style-type: none"> <li>• Systemic Lupus Erythema</li> <li>• Dermatomyositis</li> <li>• Rheumatoid Arthritis</li> <li>• Scleroderma</li> <li>• Polyarteritis Nodosa</li> <li>• Electrolyte Imbalance</li> </ul>
Post-Cancer Treatment	<ul style="list-style-type: none"> <li>• Radiation</li> <li>• Drugs (Anthracyclines, Cyclophosphamide)</li> </ul>
Maron et al (2006, p. 8)	

The number of different ways in which heart failure can be defined is not simply an issue of semantics but has practical implications in terms of service development and delivery, the collection of epidemiological data and, not least, the patient and their family. In relation to GP funding, only the specific term Left Ventricular Systolic Dysfunction (LVSD) is currently recognised as heart failure. The likely outcome of this is to limit the number of people diagnosed, with subsequent limitation of resources. However, the inclusion of Heart Failure with Preserved Ejection Fraction (HF-PEF) in the new NICE (2010) guideline may go some way to redress this in the future.

### **2.1.2 Epidemiology of heart failure**

Despite recent advances in the understanding of heart failure, it is not a new condition. Symptoms are described in classical literature and the Romans described the therapeutic and toxic effects of foxglove (*digitalis*) on the heart. In 1795, a Birmingham physician, William Withering, published a case study on the treatment of a patient with 'dropsy' (believed to be heart failure) with *digitalis* (Nicholson, 2007).

Epidemiological data on heart disease is collated regularly by the British Heart Foundation (BHF) and published as 'heartstats' ([www.heartstats.org](http://www.heartstats.org)). The General Practice Research Database (GPRD) describes incidence increasing with age with a 60% higher incidence of heart failure amongst men, compared to women. 28,000 new cases of heart failure per year are estimated (Scarborough et al, 2010).

In relation to prevalence, NICE (2003) gives prevalence rates of 3-20 people (0.3-2%) per 1,000 in all age groups and 30-130 per 1,000 (3-13%) in those over 75 years of age. The Hillingdon Heart Study found a prevalence rate of 0.9% rising to 7.4% (Cowie et al, 1999). The MONICA study conducted in Glasgow, found a rate of 1.2-2.9% (McDonagh et al, 1997). The Heart of England Study (Davies et al, 2001), conducted in the West Midlands, estimated the overall prevalence of heart failure to be over 2% with a further 1% with 'probable' heart failure. Prevalence rates were between 6-7% in those aged 75 to 84 years, increasing to between 12-22% in those aged 85 years and over. The GPRD estimates overall prevalence rates to be 0.9% in men and 0.7% in women. In those aged over 75 years, prevalence rates rise to 13.7% in men and 12.5% in women (Scarborough, 2010). NICE (2010) predict that the number of people with heart failure will rise due to increasing survival rates for CHD, more effective treatments for heart failure and an ageing population. Added to this is the likelihood that more patients will be diagnosed with heart failure as the availability of diagnostic investigations increase (Nicholson, 2007).

The total annual cost of heart failure to the NHS has been estimated at around 2% of the total budget with 70% of these costs due to hospitalisation (Petersen et al, 2002). The



number of in-patient episodes in 2008/9 has been recorded as in excess of 100,000 with associated high financial costs (Scarborough, 2010). Admission rates rise steeply in those over 85 years of age and readmission rates are high with one in four patients returning to hospital within three months (Cleland et al, 2003). Admission rates are predicted to rise by 50% over the next 25 years as the prevalence of the disease increases (Petersen et al, 2002).

Primary care costs are also high with the cost of GP consultations estimated at £45 million per year. Community-based drug therapy is estimated to cost £129 million per year (Stewart and Horowitz, 2002). Financial costs to the individual are more difficult to quantify but may arise from prescription costs, attendance at clinics, hospital stays, loss of earnings and required modifications to the home (NICE, 2010).

The prognosis for heart failure is poor. The Hillingdon Heart Study (Cowie et al, 1999) found that 40% of people died within the first year following diagnosis although there is evidence of an improving picture with six month mortality falling from 26% in 1995 to 14% in 2005 (Mehta et al, 2009). Mortality is less than 10% per year, thereafter (Hobbs et al, 2007). Within the context of other life-threatening illnesses, the prognosis in heart failure is worse than many types of cancers (Cowie, 2003). However, unlike cancer, prognostic markers are highly variable, making accurate prediction of prognosis difficult. The severity of the illness is best indicated by echocardiography findings. In addition, the New York Heart Association (NYHA) functional classification of heart failure (NYHA, 1984) (Table 2.2), indicates decreasing functional ability from classes I to IV where class IV represents the most limited functional ability due to symptoms.

**Table 2.2**      **The New York Heart Association (NYHA) Functional Classification of Heart Failure**

<b>Class</b>	<b>Patient Symptoms</b>
<b><i>Class I</i></b> (mild)	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitations or dyspnoea.
<b><i>Class II</i></b> (mild)	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitations or dyspnoea.
<b><i>Class III</i></b> (moderate)	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitations or dyspnoea.
<b><i>Class IV</i></b> (severe)	Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.
NYHA (1984, p.254)	

However, the NYHA classification has limited ability to accurately predict prognosis with patients classified as IV being stable for many years or those classified at II or III dying earlier than expected. The reasons for this are complex, not least because of the high degree of subjectivity in assigning classification. It has been noted that the patient's view of the severity of their illness according to functional ability, is poorly correlated with their doctor's assessment of their NYHA classification (Subramanian et al, 2005). The risk of sudden death due to an arrhythmia at any stage of heart failure is also a complicating factor.

Biochemical markers have some use in determining prognosis, specifically B-type Natriuretic Peptide (BNP) or N-terminal pro-B-type natriuretic peptide (NTproBNP) as well as measures of end-organ dysfunction such as renal failure (Nicholson, 2007). Such difficulties in predicting an accurate prognosis may mean that clinicians are reluctant to discuss end of life care with patients and their families which may add to a belief that the condition is not serious (Barnes et al, 2006).

The presence of co-morbidities is common in patients with heart failure. CHD is three times more common than in the wider population and diabetes is twice as common. Depression is also prevalent. The prognosis for those with multiple morbidities is worse than for those without co-morbidities (Thomas and Velazquez, 2005).

The progression of heart failure can be unpredictable. Patients may have poor functional ability on diagnosis which may improve with treatment. Patients may also become acutely ill during periods of decompensation when the heart's ability to provide an adequate circulation is compromised. Although a recovery can be made, often individuals never quite regain their previous functional level. Functional level continues to deteriorate with more frequent periods of decompensation until eventually the heart cannot compensate and the patient dies. It has been suggested that given the poor functional level of patients with heart failure throughout their illness, their last day is often no different from any other (Cowie, 2008).

### **2.1.3 Causes, symptoms and the diagnosis of heart failure – a health professional perspective**

Establishing the cause of heart failure is clinically important since some causes are reversible such as anaemia or thyrotoxicosis, or can be markedly improved by valve surgery, for example. Similarly, prognosis varies according to underlying pathology. Establishing a cause may also be important from a patient perspective in order to understand their illness. Many patients will have had chronic heart failure for a number of years and may also have co-morbidities which can make it difficult to establish an actual

or probable cause. As a result, the aetiology of heart failure is unknown in 20% of cases (Fox et al, 2001).

Where the cause of heart failure is known, it is most commonly due to CHD, with hypertension, valve disease, cardiac arrhythmias, alcohol, infection, diabetes, genetic conditions and drug-induced heart failure also documented. Rare causes of heart failure include congenital abnormalities, pregnancy, amyloidosis and sarcoidosis (Cowie et al, 1999).

CHD, particularly myocardial infarction (MI), is the most common cause of heart failure by far. Fox et al (2001) found that heart failure was caused by CHD in 52% of cases in those less than 75 years of age. In this study, CHD was confirmed by angiography and the authors suggest that the diagnosis of CHD is underestimated in people who have not had angiograms carried out. Other studies suggest CHD accounts for between a half and three quarters of cases (Zannad et al, 1999; Mair et al, 1996). The DH (2003) suggests that in the UK, most cases of heart failure are due to CHD with about one third due to hypertension. An increasingly elderly population and advances in the management of MI has meant that more people are living longer with the effects of cardiac damage. The relationship between MI and heart failure is complex with pathological changes occurring over time leading to changes in the size and shape of the myocardium, known as cardiac remodelling. The result is a larger but less effective ventricular pump (Nicholson, 2007). The role of angina in the development of heart failure is less clear. Ongoing ischaemic episodes, characteristic of angina, may have a negative effect on cardiac contraction and precipitate heart failure (Elhendy et al, 2005). Furthermore, a number of established risk factors for CHD are also independent causes of heart failure, most notably diabetes and hypertension. As a result, multiple causes of heart failure may co-exist. The Framingham study, a large scale, US longitudinal study of heart disease, found that over 90% of patients with heart failure had CHD and/or hypertension (Kannel and Belanger, 1991).

Hypertension is believed to be the second most common cause of heart failure in the developed world (Meredith and Ostergren, 2006). Fox et al (2001) found CHD to be the prime cause of heart failure but hypertension was present in 40% of patients. Whilst severe, malignant hypertension can occur, it is likely that chronic hypertension is the cause of most hypertension-related heart failure. In hypertension, the structure and function of cardiac muscle fibres is thought to be altered. Increased afterload or the pressure against which the heart has to pump is increased. This results in myocardial fibres becoming over-stretched and cardiac remodelling occurs (Nicholson, 2007). Hypertension may be more closely related to diastolic rather than systolic dysfunction

(Chinnaiyan et al, 2007). Hypertension is frequently 'silent' with no symptoms and is thought to be under-diagnosed and sub-optimally managed. Even in a patient in whom hypertension has been controlled, damage to the myocardium may have occurred before treatment commenced. Furthermore, even if the blood pressure is normal, this may have fallen as a result of pump failure - so-called 'burn-out' hypertension (Nicholson, 2007). Determining hypertension as a cause of heart failure can, therefore, be difficult.

Valve disease is another significant cause of heart failure. Figures vary from 7% of cases in the Hillingdon Heart Study (Cowie et al, 1999) to 10% in the study by Fox et al (2001). However, establishing valve disease as a cause is also problematic as valve abnormalities can be a consequence of heart failure due to distortion of the valves leading to problems with the flow of blood through the heart. Valve disease caused by rheumatic fever, infection or MI, for example, can be a cause of heart failure as reduced efficiency of the valves leads to changes in pressures within the chambers of the heart which over time, leads to structural changes, hypertrophy and cardiac remodelling with resultant loss of function (Nicholson, 2007).

Cardiac arrhythmias, like valve disease, can be both a cause and consequence of heart failure. Arrhythmias, especially atrial fibrillation, can cause permanent structural and functional abnormalities of cardiac muscle as turbulent blood flow through the heart reduces its efficiency. As a consequence of heart failure, atrial fibrillation is brought about by the abnormal structure and functioning of cardiac muscle leading to abnormal conduction and chaotic electrical activity. Fox et al (2001) identified lone atrial fibrillation as the cause of heart failure in 3% of cases. In the Hillingdon Heart Study up to 30% of people with heart failure had atrial fibrillation either as a cause or consequence of the illness (Cowie et al, 1999).

Alcoholic cardiomyopathy may develop in patients with a history of excessive alcohol intake. Alcohol alone is believed to be the cause in 4% of cases of heart failure (Fox et al, 2001). The mechanism is dependent on the toxic effect of alcohol on the heart causing cellular damage and cardiac dilation. With early abstinence from alcohol this damage may be reversible (Nicholson, 2007).

Causes such as infection, diabetes, genetic illnesses and drugs make up approximately 5% of heart failure cases (Fox et al, 2001). Though uncommon, acute viral myocarditis is the primary cause of heart failure in younger patients (Burian et al, 2005). The coxsackie virus is the most common agent but measles, mumps, rubella, and chickenpox are also potential causes. Other infective disorders are rheumatic fever, Chagas disease and human immunodeficiency virus (HIV) (Burian et al, 2005). Where infection is the cause,

patients may become very ill, very quickly with acute heart failure and life-threatening arrhythmias. Diabetes may be an independent cause of heart failure in that the metabolic effects of poor glycaemic control can cause remodelling of the myocardium and dilated cardiomyopathy (Bertoni et al, 2006).

Some specific types of cardiomyopathy, such as Hypertrophic Obstructive Cardiomyopathy (HOCM), are due to a genetic abnormality and are hereditary. Patients often present at a young age with symptoms of heart failure or related complications such as arrhythmias. Unfortunately, the first indication of this may be sudden death. Individuals may be identified through family screening, especially when sudden cardiac death has occurred in the family. Heart failure may also be iatrogenic. Chemotherapy, for example, can cause damage to myocardial cells. Acute cytotoxicity in the first year following treatment is thought to occur in up to 50% of patients. Long-term effects are also observed (Nicholson, 2007).

Although currently uncommon, the number of heart failure patients with congenital heart abnormalities is likely to increase. For the first time, there is now a population of young adults who have had cardiac surgery in infancy. The long-term consequence of this, for some patients, is heart failure (Nicholson, 2007). Heart failure in pregnancy is also rare occurring in 1 in 2,400 to 1 in 15,000 births in the western world. It is a recognised cause of maternal death before, during and in the first few months following delivery (Fox et al, 2001). The mechanism is unclear although it may be due to the haemodynamic stress of pregnancy and birth or a response to an immunocological breakdown between the mother and the foetus leading to cardiac inflammation (Nicholson, 2007). Amyloidosis and sarcoidosis are systemic diseases which are also rare causes of heart failure occurring when amyloid or sarcoid tissue infiltrates the myocardium leading to fibrosis and impaired contractility (Nicholson, 2007).

Given the difficulties in determining the cause of heart failure, recognising symptoms and clinical signs is especially important for diagnosis. Symptoms are the subjective experience of sensations as described by patients. In contrast, signs are objective, clinical observations. The recognition of signs and symptoms that have high sensitivity and specificity for heart failure is a key requirement for diagnosis and treatment. A number of large studies have sought to identify symptoms relating to heart failure. In these studies, the most prevalent symptoms of heart failure were identified as breathlessness, particularly on exertion (Ahmed et al, 2004; Badgett et al 1997; Harlan, 1977) and peripheral, ankle oedema (Ahmed et al, 2004; Fonseca et al, 2004; Badgett et al 1997;

Davie et al, 1996; Harlan, 1977). NICE (2010) identify breathlessness, fatigue and ankle swelling as the most common symptoms of heart failure.

Breathlessness, described as difficulty in breathing (dyspnoea) or shortness of breath, can occur on exertion or at rest and is commonly experienced when lying flat (orthopnoea). However, not all patients with heart failure experience breathlessness and this symptom may exist for many other reasons. The origin of breathlessness in heart failure is multi-faceted. Impaired cardiac function means that the increased oxygen demands of the body during exercise cannot be met. As a result, the exercise threshold is reached early with increasing breathlessness and resulting poor exercise tolerance. Breathlessness at rest occurs in severe heart failure and may result from the reduced ability of the left ventricle to empty, leading to a build-up of fluid and increased pressure in the lungs which forces fluid out of the pulmonary circulation into the alveoli with subsequently reduced gaseous exchange and hypoxaemia. Patients may be told they have 'fluid on the lungs'. The presence of white or blood-stained, frothy sputum and a cough is associated with dyspnoea as a result of fluid-build up.

Alternatively, breathlessness at rest may be due to chronic increased pressure in the lungs causing the lungs to become inelastic. In this case the lungs may be described as 'dry'. A wheeze may be heard which can lead to a respiratory disorder being erroneously diagnosed. Worsening of dyspnoea in heart failure is often due to complicating factors such as a chest infection. Orthopnoea is a prevalent symptom in heart failure, consequently, patients may sleep upright with a number of pillows or sleep in an armchair. In severe heart failure, paroxysmal nocturnal dyspnoea may occur where patients report waking suddenly, a few hours after going to bed, in a state of extreme breathlessness and anxiety. Both orthopnoea and paroxysmal nocturnal dyspnoea are more specific symptoms of heart failure than breathlessness alone. Other sleep disturbances have been described, for example, insomnia and sleep apnoea have been linked with increased disease severity and poor prognosis (Merritt, 2004).

Systemic fluid retention is another classical symptom of heart failure. Fluid retention occurs as a compensatory physiological response to a falling cardiac output. This excess fluid is forced into the tissues as a result of osmotic and hydrostatic forces. Commonly, this occurs in the ankles due to the effects of gravity. If fluid continues to build-up, it is forced higher into the sacrum and abdomen (ascites) leading to nausea and loss of appetite. The first detectable sign of fluid build-up is often weight gain. Patients may notice clothes feeling tight or difficulty in putting shoes on. Ankle oedema is bi-lateral and

described as 'pitting' where the tissue is soft and can be compressed leaving an indentation which persists for several minutes (Nicholson, 2007).

Ahmed et al, (2004) have documented fatigue or tiredness as a prevalent symptom of heart failure. The cause of fatigue may be due to a number of factors both physical and psychological. Reduced blood flow to skeletal muscle with resulting poor exercise tolerance may be one factor (Jackson et al, 2000). Depression, prevalent in heart failure, may also result in feelings of tiredness. Poor quality of sleep due to symptoms and the effects of medication, especially diuretics, may be contributing factors.

Sexual dysfunction has been cited as a symptom of heart failure and it is likely that this is more common than documented due to a lack of reporting. Reduced peripheral circulation may impair sexual functioning. The use of drugs commonly used in heart failure such as Angiotensin Converting Enzyme Inhibitors (ACEI) and beta-blockers may further reduce blood supply or affect libido directly. Depression may be a contributing factor (Leventhal et al, 2005). Cognitive impairment is reported in heart failure due to chronic under-perfusion of the brain. Forgetfulness, difficulty in making decisions, light-headedness or dizziness are well documented (Bennett and Sauve, 2003).

As well as symptoms which can be attributed to heart failure, a number of other symptoms frequently co-exist. Arrhythmias, experienced as palpitations, dizziness or blackouts (syncope) can be a cause or consequence of heart failure. The presence of CHD may mean that symptoms such as chest pain also occur.

Clinical signs of heart failure include changes in haemodynamic parameters of pulse including rate, regularity, character and volume, changes in blood pressure and a raised jugular venous pressure. A third heart sound (S3), a gallop rhythm and a displaced apex beat may be heard on physical examination as well as lung crepitations and a wheeze (Ahmed et al, 2004; Fonseca et al, 2004; Drazner et al, 2003; Badgett et al, 1997; Davie et al, 1996; Harlan, 1977). Anaemia may be present as a consequence of reduced blood flow to the gut resulting in lack of iron absorption and signs of malnutrition.

Along with an exploration of symptoms and physical examination, patients may undergo a number of investigations to confirm a diagnosis of heart failure. According to NICE (2010), those with a clinical history of heart failure and previous MI should be referred for an echocardiogram, reflecting the significance of MI as the most common cause of heart failure in the UK. In those without a previous MI, a blood test to detect BNP or NTproBNP is advocated which, if positive, should prompt a referral for an echocardiograph. Other

investigations include a 12-lead electrocardiogram (ECG), chest x-ray and further blood tests to monitor organ function.

NICE (2010) emphasise that a full evaluation of the patient is required which includes the identification of the underlying abnormality of the heart, the severity of the illness, the cause, precipitating and exacerbating factors, identification of co-morbidities and estimation of prognosis.

#### **2.1.4 The management of heart failure**

The management of heart failure can be considered in terms of pharmacological interventions and invasive procedures. Medicines have been described as '*The mainstay of heart failure management. They have a positive impact on symptoms, quality of life and prognosis*' (Nicholson, 2007, p.135).

There is an extensive evidence base with explicit recommendations in England and Wales from NICE (2010), in relation to drug therapy. Angiotensin II converting enzyme inhibitors (ACEIs) and beta-blockers are advocated as first line treatment in heart failure. An angiotensin receptor blocker is recommended in those intolerant of ACEIs. Second line treatment includes aldosterone antagonists, diuretics and hydralazine in combination with nitrates and digoxin. The types of medicines, their actions and potential side-effects are outlined below.

ACEIs have revolutionised the management of heart failure and are recommended in all patients due to their significant ability to improve symptoms, prognosis and reduce hospitalisation rates (Cowie et al, 1999). ACEIs competitively block the actions of angiotensin converting enzyme leading to vasodilation and reduced workload of the heart. The action of aldosterone is also blocked leading to salt and water excretion and reduced fluid build-up. As a result, ACEIs improve symptoms of breathlessness and oedema and also prevent cardiac remodelling in the longer term. The most significant side-effects of ACEIs are hypotension and resulting dizziness, renal dysfunction, electrolyte imbalances and a dry, irritating cough. ACEIs are started at a low dose and titrated upwards to a target dose as tolerated – a 'start low, go slow' approach to medication management (NICE, 2010). Angiotensin receptor blockers work in a similar way to ACEIs but block angiotensin II receptors rather than angiotensin converting enzyme, producing fewer side-effects. Angiotensin receptor blockers may be used in patients who cannot tolerate an ACEI or as second line treatment if symptoms persist (NICE, 2010).

Like ACEIs, the evidence base for beta-blockers is extensive with proven mortality benefits (Cowie et al, 1999). Beta-blockers reduce the workload of the heart by



competitively blocking the receptor sites for adrenalin and reducing heart rate and blood pressure. Ventricular filling time is increased leading to improved contractility. The potential for arrhythmias is also reduced. Bronchospasm is a serious side effect and the heart rate may be slowed to such an extent that bradycardias and heart blocks develop. Hypotension, peripheral coldness, impotence and depression are recognised side-effects (British Medical Association, 2010). As with ACEIs, beta-blockers are commonly up-titrated to a target dose as tolerated.

Aldosterone antagonists block the effects of aldosterone, preventing fluid build-up and improving symptoms and prognosis in moderate to severe heart failure (Cowie et al, 1999). Complications of aldosterone antagonists include a potassium imbalance with a resulting increased risk of cardiac arrhythmias.

Diuretics are prescribed to remove excess systemic and pulmonary fluid and to prevent fluid retention. Hence, they improve symptoms of breathlessness and oedema. They also have a vasodilator effect so that preload and cardiac workload is reduced. Diuretics can cause renal dysfunction due to a primary effect on the kidneys and reduced blood pressure. Over-diuresis can lead to dehydration, electrolyte imbalance, postural hypotension and resulting dizziness (Nicholson, 2007).

The combination of hydralazine and nitrates also has vasodilatory effects, reducing the work of the heart and improving symptoms and long-term mortality, especially in patients of African or Caribbean origin with moderate to severe heart failure (NICE, 2010). Digoxin is used to reduce heart rate and improve cardiac contractility. Historically the main drug used in heart failure, its use is now largely confined to patients with atrial tachycardias.

A number of medicines are contra-indicated in heart failure, the most important of which are non-steroidal anti-inflammatory drugs (NSAIDs) which increase fluid retention. NSAIDs, for example, ibuprofen, are common analgesic, anti-inflammatory and anti-pyretic drugs and are frequently found in over-the-counter analgesics and cold and flu remedies.

Invasive treatments are becoming more frequently used in patients with heart failure. These can be summarised as either cardiac surgery or pacemaker devices. Cardiac transplant is the only curative procedure available for heart failure but has been likened to throwing a single lifeboat to a sinking Titanic! (Cowie, 2008). The lack of available donors and the unsuitability of most patients with heart failure to undergo major cardiac surgery mean that transplantation is not a realistic option for the majority of patients. Only 200-300 patients underwent cardiac transplantation in 2009, of which only 14% of recipients were

over 60 years of age ([www.uk.transplant.org](http://www.uk.transplant.org)). Valve repair or replacement with a synthetic valve is possible where valve disease is the cause of heart failure. Cardiac assist devices or intra-aortic balloon pumps are used mainly in patients with severe heart failure as a bridge to transplantation.

The insertion of a permanent pacemaker to regulate the heart rhythm is a routine intervention in heart failure patients with arrhythmias. Increasingly, internal cardioverter defibrillators (ICDs) are inserted to terminate life-threatening arrhythmias. Cardiac resynchronisation therapy or bi-ventricular pacemakers are used to co-ordinate muscle contraction and enhance cardiac output in moderate to severe heart failure. Cardiac resynchronisation is now frequently combined with a defibrillator function (NICE, 2010).

Recommendations for monitoring the patient with heart failure are also given by NICE (2010). These include an ongoing assessment of functional ability, fluid status, heart rhythm, cognitive and nutritional status, regular review of medication including side-effects and blood tests to monitor electrolytes and renal function. The frequency of monitoring is dependent on the clinical stability of the patient. Although monitoring is largely seen as the responsibility of the health professional, patient-initiated electronic telemonitoring, where physiological data are transferred from the patient's home to the healthcare provider is now becoming more common. However, NICE (2010) conclude that further research is needed to determine whether telemonitoring adds any benefit over care by a specialist, multi-disciplinary heart failure team.

The involvement of specialists and the multi-disciplinary team in continuing care are pivotal in the management of patients with heart failure (NICE, 2010). The creation of the specialist heart failure nurse (HFN) role, largely funded and supported by the British Heart Foundation, through a £10 million grant from the New Opportunities Fund, seems to support this view.

Sometimes, in spite of optimal management, there may come a point when patients reach the terminal or end-stage of their illness. The move to a palliative approach can be problematic as the course of the illness may be difficult to predict, as previously discussed. A palliative approach focuses on relieving symptoms, removing treatments that are no longer necessary and reducing suffering through physical, psychological and spiritual support. Diuretics, nitrates, opiate analgesics, saline nebulisers and breathing exercises can alleviate symptoms of breathlessness. Non-invasive ventilation may improve breathing if it can be tolerated by the patient. Sedatives aid sleep. Dietary modification, anti-emetics and laxatives alleviate symptoms of nausea and constipation as blood flow to the gut is reduced. Liquid food supplements may improve cachexia.

Issues of resuscitation need to be addressed, specifically, ICDs need to be de-activated. The psychological and spiritual needs of the patient should to be determined and addressed through advice, referral and actively sharing the experience of the patient and their family (NICE, 2003). Specialist palliative care services have largely been developed for patients with cancer and as such have traditionally been unavailable to patients with heart failure. However, this is changing with the recognition that access to palliative care should be available to all dying patients regardless of the disease pathology (NICE, 2003).

Whilst medical, nursing and social care dominates the management of heart failure, there is growing recognition that patients should be involved in managing their illness. A partnership in care is envisaged with the patient, their family and health and social care professionals playing important roles. As well as adhering to medication regimes and monitoring and managing the effects of medication, it is advocated that patients adjust their lifestyle to take regular exercise, stop smoking, limit their alcohol intake, follow a balanced diet, reduce salt in their diet, limit fluid intake and monitor their fluid status (NICE, 2010; Nicholson, 2007). Exercise-based rehabilitation programmes and local support networks have been set up to facilitate this (NICE, 2010). The DH (2003), rather optimistically, suggests that patients who have a proper understanding of their condition and the role of different drugs are more likely to comply with their medication and to identify problems such as excessive weight gain early, and so are less likely to require admission to hospital.

In conclusion, heart failure is a significant clinical condition which is predicted to become more widespread in the future. Healthcare costs are high and increasing. The level of functioning of patients with heart failure is poor and prognosis may be difficult to predict. Identifying the many types and causes of heart failure is difficult not least because of the relationship between cause and effect. Therefore, recognising the symptoms and clinical signs of heart failure is especially important. Management is mainly pharmacological although surgical and other interventions, such as pacemaker devices, are becoming increasingly common. There is an established evidence base, articulated by NICE (2003; 2010) in relation to the diagnosis and management of heart failure. Within this, it is recognised that patients should play an active role in the management of their condition.

In contrast to the biomedical view of the disease as discussed in this section, there follows a discussion of the literature regarding lay beliefs and social and psychological perspectives of health, illness and treatment.

## **2.2 LAY BELIEFS OF ILLNESS AND THE COMMON SENSE MODEL (CSM) OF ILLNESS COGNITIONS AND BEHAVIOUR**

This section begins by introducing lay beliefs about illness before discussing the common sense model (CSM) of illness cognitions and behaviour (Leventhal et al, 1980). The theoretical basis of treatment beliefs according to Horne (1997) and the relationship to the CSM will be analysed. The measurement of illness and treatment beliefs is also discussed.

### **2.2.1 The experience of illness and the nature of lay beliefs**

Since the 1950s there has been a move away from a purely biomedical perspective of disease where there is an objective pathology and recognised signs, symptoms and time course, in favour of the concept of illness.

Illness is defined by Kleinman (1988, p.3) as:

*‘The innately human experience of symptoms and suffering, referring to how the sick person and the members of the family or wider social network perceive, live with and respond to symptoms and disability’*

In sociological literature, a number of studies have been instrumental in contributing to the understanding of the illness experience from a social perspective. Glaser and Strauss (1967) described an illness trajectory which referred not just to the course of the illness but also to the work associated with it and the impact of this work on relationships. In long-term conditions such as heart failure, the expectation of self-care and the need for frequent monitoring of the illness and its treatment may constitute a significant burden for the patient and their family.

Bury (1982) described the experience of chronic illness in terms of biographical disruption, arguing that the experience of illness led to a fundamental rethinking of the individuals' biography and self-concept. A biographical shift was described from a perceived normal trajectory with relatively predictable chronological steps to one which was abnormal and damaging. In heart failure and other long-term conditions, the presence of debilitating symptoms may require individuals to give up paid employment resulting in disruption to financial, social and psychological well-being. Bury (1982) also argued that biographical disruption affected not only the individual but also their relationships and practical aspects of life. Social networks and other resources were seen as crucial in determining how the illness was perceived. In heart failure, the effects of the illness may conceivably lead to a

greater reliance on close family members for emotional and practical support with a resultant change in social roles.

Related to biographical disruption is the concept of loss of self, where former self-images are destroyed leading to restricted lives, social isolation and the feeling of being a burden to others (Charmaz, 1983). This theory was developed further by Williams (1983) who described the strategies people employed to create a sense of coherence and stability when faced with biographical disruption and loss of self. In heart failure, this search for stability is illustrated by Zambroski (2003) who described living with heart failure as navigating periods of turbulence before finding safe harbour through lifestyle changes and social re-adjustment.

Viewing illness from an individual or 'insider' perspective is integral to our understanding of the illness experience. Helman (1978) describes this as the 'emic' perspective in which lay beliefs are central. Hughes (1968, p.88) defines lay beliefs about illness as:

*'Those beliefs and practices relating to disease, which are the products of indigenous cultural development and are not explicitly derived from the conceptual framework of modern medicine'*

Russak and Friedman (1970) advanced this understanding by demonstrating that there were often fundamental differences between the biomedical and social understanding of illness in terms of causation, treatment and time-course, for example. Similarly, Kleinman's work in the 1970s and 1980s challenged the biomedical view of what it means to be ill, highlighted cultural and societal beliefs in the illness experience (Kleinman, 1988). Using case study examples, Kleinman argued that cultural influences and social norms helped shape individual beliefs about illness. This unique, personal understanding is in contrast to the view of disease as biologically determined and therefore, consistent and universal between individuals. As a result of these alternative viewpoints, there is the potential for conflict between the health professional and the patient in terms of the nature of the illness and the way in which it is best treated. This not only has implications for the relationship between the professional and the patient but also potentially, adherence to treatment. In recognition of this, Kleinman (1988) envisaged a model of clinical consultation consisting of an exploration of the patient's illness and treatment beliefs before the development of a negotiated treatment plan. Such a model illustrates the concept of concordance, or the process by which beliefs about the illness and its treatment are shared in an equal partnership between the individual and health professional (DH, 1997).

A number of explanatory models have been developed to categorise the nature of lay beliefs. Blumhagen (1980) argued that people seek explanations for the illness in terms of aetiology, the timing and mode of onset, the pathophysiology, the time-course, the degree of sickness and its treatment. Similarly, Kleinman (1988) developed an explanatory model consisting of the nature of the illness or symptoms, reasons for the onset of symptoms at a particular time, causes of the illness, expected time-course, seriousness, the way in which the illness affected the patient's life and fears about the illness. Issues of perceived risk, vulnerability, compliance and satisfaction with care were seen as contributing factors to the development of beliefs. Rather than being formally organised, Kleinman (1988) argued that explanatory models were often incoherent and ambiguous and were time and context specific. He argued that these models were often only constructed by the patient as a result of telling a narrative of their illness experience.

Exploring lay beliefs is not, however, straightforward. Shaw (2002) argues that in western society, lay narratives of illness are in fact, accounts that have been filtered through medical or other health professionals and then owned by patients. That is, people re-define their illness in line with professional definitions. He argues that in searching for meaning, people adopt expert, professional explanations and interpretations about their illness. Hence, patients may attempt to describe and explain their heart failure using medical terminology which may be poorly understood. Another difficulty in accessing lay beliefs, according to Cornwell (1984), is the disparity which may exist between patients' public and private accounts of their illness. Public accounts focus on widely accepted views which are likely to gain approval from, and be congruent with, the professional's viewpoint. Those opinions which might be considered unacceptable to the medical professional are not expressed, so that conflict is avoided.

The assumption that the beliefs people hold about their illness relate to their behaviour or actions in some way, is important in terms of their influence on clinical outcomes. Although it has been suggested that beliefs may be employed as *ex poste facto* explanations of behaviour rather than as predictors of it (Dines, 1994), most authors, including Leventhal et al (1980), argue that beliefs influence and predict illness behaviours such as taking medication, visiting the doctor in response to symptoms or avoiding health-damaging behaviours. As such, lay beliefs about health and illness form the foundation of a number of theoretical models which aim to explain and predict changes in health and illness behaviour.

In summary, in contrast to a biomedical model of disease, the illness experience can be viewed from a sociological perspective in terms of biographical disruption and loss of self.

The study of lay beliefs enhances our understanding of the personal experience of illness or an emic perspective, and explanatory models such as that of Blumhagen (1980) and Kleinman (1988), have provided a general framework for examining lay beliefs. However, difficulties may exist in determining lay beliefs not least because of the prevailing medical culture in western society. Finally, lay beliefs are assumed to influence behaviour. The following section introduces the Common Sense Model (CSM) which has been developed from lay beliefs and used to explain and predict health and illness behaviour.

### **2.2.2 The Common Sense Model (CSM) of illness cognitions and behaviour**

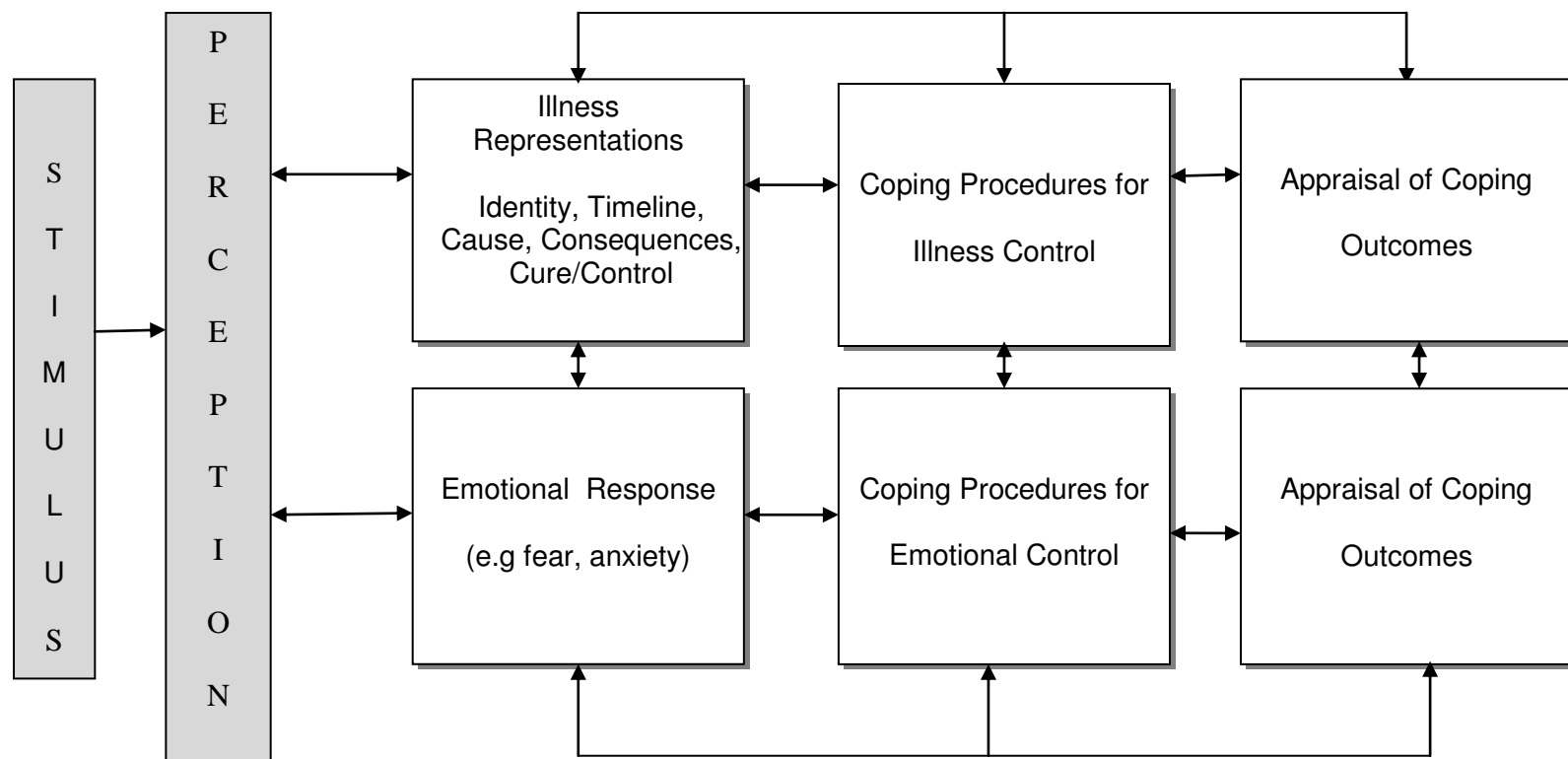
The common sense model (CSM) of illness cognitions and behaviour (Leventhal et al, 1980) describes a process of self-regulation which involves goal setting, developing and enacting strategies to achieve these goals, appraising progress and revising goals and strategies (de Ridder and de Witt, 2006). Self-regulation is viewed as a dynamic, motivational system in which the management of emotional responses to the illness are also seen as important and intricately linked to cognitive processes.

Historically, Leventhal and colleagues explored the concept of fear in influencing smoking behaviour. They found that whilst fear messages had some short-term effects in terms of behaviour, this was not maintained over time (Leventhal et al, 1997). They hypothesised that the processing of the health threat was separate from the processing of the fear emotion. The authors called this the 'parallel response model'. In the subsequently developed CSM, they explored the factors that led to the development of coping behaviours and called them 'cognitive representations of illness' or 'illness representations'. They argued that these representations were generated in the minds of individuals and not imposed by the researcher. In this way, the CSM emphasises what the authors believe are intrinsic, personal, 'common sense' beliefs about illness.

The model is organised into three stages. Stage one is the 'identification' stage which consists of illness representations and emotional responses. Stage two is 'coping behaviours' which are generated in response to illness representations and emotional responses and stage three is the 'appraisal' of these coping behaviours (Figure 2.1)

The perception of stimuli, such as the occurrence of symptoms or health information, initiate illness representations so that the individual forms a picture of the condition based on current symptoms, contextual information and pre-existing beliefs. This guides the selection of coping responses, the outcomes of which are appraised in terms of eliminating the health threat, or controlling the illness or its consequences. Similarly, processing of the initial stimuli leads to the development of an emotional response which prompts the selection of coping responses aimed at controlling these emotions.

Figure 2.1 The Common Sense Model (CSM) of Illness Cognitions and Behaviour (Leventhal et al, 1980)





More recently, the concept of coherence is believed to be important within the model. Cameron and Leventhal (2003) describe this as the *'if-then'* scenario. For example, *'if I am suffering from a headache due to stresses at work today then taking two aspirin will eliminate the pain within 20-30 minutes'*. In this way, a coherent picture of the illness and the behaviour is built up. If the illness representations, coping procedures and outcome enable the individual to form a consistent and coherent schema of the illness and its treatment, then beliefs and behaviour are reinforced.

The model is self-regulatory in that it assumes that the individual is motivated to resolve the health threat and return to normality. This is achieved through the existence of feedback processes where appraisal of coping responses feed back to the illness representations, modifying beliefs which may lead to the selection of alternative coping responses.

A number of assumptions are inherent within the model. Firstly, that people are active problem solvers who use past experience and existing knowledge to formulate and respond to a health threat. Secondly, many of the cognitive processes are not directly observable, rather observers make inferences based on what individuals say and do. Thirdly, the behaviour is both time- and situation-specific, that is, the process of constructing a representation of the illness and responding to it occurs within a specific time frame and contextual situation (Leventhal et al, 1980).

In relation to the stages of the model, stage one, identification, consists of two sets of beliefs – illness representations and emotional responses to the illness. Illness representations are defined as *'an organised set of beliefs regarding illness'* (Cameron and Moss-Morris, 2004, p.85). Scharloo and Kaptein (1997) propose that a number of other terms are synonymous with illness representations including illness cognitions, illness perceptions, illness beliefs and illness schemata. For the purpose of this thesis, the term illness representations will be used as they relate to the CSM.

Lau and Hartmann (1983) identified five illness representations: identity, cause, timeline, consequences and cure and control. Bishop (1991), cited by Leventhal et al (1997), found that, when patients were asked to describe their experience of illness, 90% of responses fell into these five categories. The CSM incorporates these five key dimensions of illness representations as summarised in Table 2.3.

**Table 2.3**      **Illness Representations According to the CSM (Leventhal et al, 1980)**

<b>Illness Representation</b>	<b>Definition</b>
<b>Identity</b>	The illness label or diagnosis and perceived associated symptoms.
<b>Cause</b>	The factors or conditions believed to have caused the illness.
<b>Timeline</b>	The expected duration of the illness which may be acute and short term, cyclical or episodic, meaning the illness or its symptoms come and go, or chronic and long-term.
<b>Consequences</b>	The perceived effects of the illness on for example, physical, social, economic and psychological well-being and beliefs about the severity or seriousness of the illness.
<b>Cure and control</b>	The extent to which the illness can be controlled or cured through treatment measures and/or personal behaviours.

Illness representations, it is suggested, are formed from a range of social and cultural influences such as media portrayal of illness, education, information from health professionals, personal and past experience of illness and the experience of illness of family or friends. Representations are not independent but related to each other (Cameron and Moss-Morris, 2004). Leventhal et al (1997) agrees that representations are organised into clusters or sets. For example, a strong belief that the illness can be cured or controlled is more likely to be associated with the belief that the illness will last a short time and have relatively minor consequences. In contrast, the belief that the illness will last a long time is likely to be associated with a belief in more serious consequences and an illness which cannot be cured or controlled.

Leventhal et al (1997) identify a number of 'rules' in the construction of illness representations based on empirical studies. These are the symmetry rule, the stress-illness rule, the age-illness rule, and prevalence and duration rules. The symmetry rule states that each representation has two levels: concrete, perceptual codes, for example, the symptoms experienced, and abstract, linguistic codes, that is, the label or diagnosis given to the symptoms. Individuals try to link these perceptual and linguistic codes to have a clearly defined profile of the illness so the experience of symptoms creates a pressure for labelling or diagnosis and a diagnosis generates pressure for the identification of symptoms (Bauman et al, 1989; Easterling and Leventhal, 1989; Meyer et al, 1985). In this way, a coherent picture of the illness is constructed.

The stress-illness and age-illness rules state that individuals will seek to determine if symptoms or functional changes reflect an underlying disease process or are stress or age related (Bauman et al, 1989). Hence, the symptom of tiredness may be attributed to

old age, headaches may be deemed the result of work stress. The duration and prevalence rules (Leventhal et al, 1997; Croyle and Jemmott, 1991) address the potential seriousness of symptoms. Symptoms of long duration and which are perceived as uncommon or rare are more likely to lead to the perception that they represent a serious illness.

Leventhal et al (1997) acknowledge that representations may be further sub-divided. For example, Moss-Morris et al (2002) suggest that control can be divided into beliefs about personal control or the belief that one's actions will help control the illness, and treatment control, the belief that medication or other medical interventions will be effective in curing or controlling the illness. Cameron and Moss-Morris (2004) hypothesise that perceptions of high treatment control may predict adherence to medication whilst high personal control may predict lifestyle changes. Cure and control beliefs are also related to the concept of self-efficacy or an individual's confidence in their ability to carry out health-promoting behaviours (Bandura, 1977), and outcomes efficacy or the belief that a particular action is effective in achieving the desired outcome. Attribution theory (Weiner, 1986), describes the processes by which individuals explain the causes of events which can be differentiated into intrinsic and extrinsic causes.

Illness representations influence emotional responses and vice versa. For example, the discovery of a breast lump is likely to lead to an emotional response of fear and anxiety and the label 'breast cancer' may further fuel these emotions. According to the CSM, mood directly influences illness representations. For example, a positive mood may make people feel that the illness is less of a threat and there is little need for concern. A negative mood may focus the individual on an awareness of symptoms with the potential for further worry. Whilst worry may motivate the individual to health protecting behaviours, if anxiety is high, individuals may avoid coping behaviours such as seeking advice from a health professional as doing so may further provoke feelings of anxiety.

In stage two of the model, illness representations and emotional responses guide the selection of coping mechanisms or procedures to eliminate or control the illness threat. Leventhal et al (1997) tried to avoid a simple typology of 'ways of coping' such as that of Lazarus and Folkman (1984) who describe 'avoidance' or 'approach' coping responses. Rather the model attempts to describe the factors involved in selecting and maintaining these coping responses.

Coping responses or procedures deal with both the illness representations and the emotional response and are dependent on the formulation of an action plan which links illness representations and actions (Leventhal et al, 1997). The nature of these

procedures is numerous such as taking medication, resting or seeking advice. Coping procedures are complex and like illness representations, can be classified into the dimensions of identity, timeline, causal mechanisms, consequences and control expectations. For example, *'resting when I have chest pain due to my angina will relieve the pain within half an hour'*. Coping procedures also specify a class of actions such as taking analgesics and a specific choice within that such as taking paracetamol.

Stage three is the appraisal of coping procedures which completes the feedback system. If coping procedures are deemed to be effective in controlling the health threat, illness representations are reinforced. Alternatively, if coping procedures do not achieve the expected consequences within the expected timeframe for example, then the individual is motivated to reconsider both the illness representation and the coping procedures. As a result, illness representations, emotional responses and coping procedures may be altered. For example, in acute MI, chest pain may initially be attributed to indigestion and antacids taken. An appraisal of this action may lead to the belief that antacids are ineffective in relieving the chest pain and the more serious and worrying identity of a heart attack may be constructed along with an alternative coping procedure such as calling for emergency help (MacInnes, 2006; Petrie et al, 1996).

A number of moderators and mediators are identified within the model including socio-economic and individual factors. Cultural influences and the social context within which behaviour takes place are considered to be important. Leventhal et al (1997) believe that whilst culture is undoubtedly important, analysis of cross-cultural beliefs in western societies reveals more similarities than differences. In the CSM, the influence of culture is confined to differences in language which affect the labelling of the illness. Cameron and Moss-Morris (2004) argue, like Kleinman (1988), that illness is, to a large extent, culturally defined and while the biological processes of disease may be universal, cultural differences exist in terms of social norms, traditions, customs and way of life which influence the perception of symptoms and the development of illness beliefs.

The CSM has been criticised for its inability to articulate social influences except at the level of influencing illness representations (Ogden, 2003). Leventhal et al (1997, p.54) acknowledge that the model needs to be further extended into the social context but argue that *'it is a gross misconception to think of self-regulation as a process carried out in solitude or to think of the individual as an isolated problem-solving machine'*. They argue that social messages and relationships help shape not only illness representations but also emotional responses and coping behaviour. For example, media portrayal of illness and consultation with family and friends inform not only beliefs but also help to determine

the response such as the decision to seek medical help, make lifestyle changes or take medication. The illness may also be viewed in comparison to others of the same age (the age-illness rule) or the experience of others with illness.

However, Cameron and Leventhal (2003) maintain that the 'self' remains the primary agent of self-regulation in that the individual chooses whether to seek advice from others and decides whether or not to follow that advice. This may be especially true when input from social sources is inconsistent with their own beliefs and experience. Hence, although the social context influences the interpretation of symptoms and the specific responses, they do not define self-regulation entirely.

It is also argued that theoretical ambiguities exist in the assignment of illness representations and coping procedures. For example, the belief that the illness has few serious consequences may be a coping procedure rather than an illness belief (Ogden, 2003).

Whilst such conceptual difficulties undoubtedly exist, the CSM has been shown empirically to be a useful framework for examining the complex nature of health and illness beliefs and behaviour. Hagger and Orbell (2003) conducted a meta-analysis of 45 studies which used the CSM. They found support for the ability of illness representations to predict a range of outcomes such as physical functioning, psychological distress, psychological well-being, role functioning, social functioning and vitality. Pearson's correlation co-efficients ( $r$ ) were calculated between illness representations and outcomes and found to be moderate but statistically significant ( $p \leq 0.05$ ), ranging from  $r = -0.56$  to  $r = 0.50$  in the reviewed studies. The following section examines the measurement of illness representations.

### **2.2.3 The measurement of illness representations**

Leventhal et al (1980) used semi-structured interviews to explore illness beliefs in different illness populations. While this enabled in-depth explorations of beliefs, the small sample sizes and context-specific findings meant the results were not necessarily transferable to other populations or illnesses.

Weinman et al (1996) developed the Illness Perception Questionnaire (IPQ) using the CSM as a theoretical basis. Unlike earlier methods, its purpose was to enable the assessment of illness representations in large populations across different illness groups and to determine relationships between illness representations and behaviour. The questionnaire was divided into five sub-scales or domains corresponding to the five illness representations. The identify domain was assessed by listing a number of common

physical symptoms such as nausea and fatigue, and asking respondents to rate them in terms of frequency on a 4-point scale. For all other domains, respondents were asked to rate the extent to which they agreed or disagreed with a series of statements using a 5-point attitudinal scale. For example, cause: *'family problems or worries caused my illness'*, consequences: *'my illness strongly affects the way others see me'*, timeline: *'my illness will pass quickly'* and cure/control: *'there is little that can be done to improve my illness'*. Analyses of causal attributes were treated as separate statements with all other domains analysed by summing the scores.

The IPQ was evaluated for its psychometric properties in seven illness groups. Internal consistency was demonstrated by Cronbach's alpha ( $\alpha$ ). This ranged from  $\alpha = 0.73$  to  $\alpha = 0.82$  across the different domains. Test-retest reliability was demonstrated at one, three and six months. In terms of concurrent validity, in an MI sample, the IPQ correlated with several other measures of health beliefs and behaviour, for example, the Sickness Impact Profile (Bergner et al, 1981). Concurrent validity was established in the diabetes sample using the IPQ and semi-structured interviews. Assessing scores across four different illness groups determined discriminant validity. Predictive validity of the IPQ was established by predicting attendance at cardiac rehabilitation within the MI group, at three and six months follow up (Petrie et al, 1996).

Moss-Morris et al (2002) developed a revised IPQ (the IPQ-R, Appendix 1), which has improved measures of timeline and cure/control and includes additional domains of emotional response and illness coherence according to the CSM. Cyclical or episodic beliefs have been added as an additional dimension of timeline in statements such as, *'I go through cycles in which my illness gets better and worse'*. Cure/control is divided into personal control relating to self-efficacy beliefs and treatment control as a measure of outcome expectancy. For example, *'I have the power to influence my illness'* and *'my treatment can control my illness'*. Emotional responses are assessed through statements such as, *'my illness makes me feel afraid'*. The extent to which individuals' illness representations provide a coherent understanding of the illness or the extent to which it 'makes sense' has also been added. For example, *'my illness is a mystery to me'*. The authors describe illness coherence as a meta-cognition as it is not specifically related to beliefs about illness but rather to personal understanding. Changes have also been made to the way in which the domain of identity is assessed. Respondents are asked whether the symptoms they have experienced are related to their illness. The authors argue that this now differentiates between a general somatic effect and specific perceptions regarding the illness identity. The IPQ-R has also been extended to include additional causal attributes and an open question to elicit the three most important causes of the

illness for that individual. In this way, causal attributes can be grouped into categories of, for example, lifestyle factors and hereditary factors.

The IPQ-R has been psychometrically tested across eight different illness groups. Principal components analysis supported the existence of seven factors, namely, timeline (acute/chronic), timeline (cyclical), consequences, personal control, treatment control, illness coherence and emotional response. Internal consistency was improved from the original IPQ with Cronbach's alpha ( $\alpha$ ) ranging from  $\alpha = 0.79$  to  $\alpha = 0.89$  for the different sub-scales or domains. Test-retest reliability was established in the renal and rheumatoid arthritis samples at three weeks and six months with Pearson's correlation co-efficients generally over  $r = 0.5$ . The IPQ-R was also able to discriminate between the emotional response to the illness and affective traits. Discriminant validity was demonstrated by significant differences between scores in the chronic and acute pain samples. Predictive validity was established by the ability to predict adjustment to illness in the multiple sclerosis sample. In conclusion, the IPQ-R can be considered a valid and reliable measure in these samples.

The IPQ and IPQ-R, whilst comprehensive in terms of their exploration of beliefs, are lengthy and may be difficult for some patients to self-complete. Arguably, they are most useful for research rather than for use in clinical practice. The Brief IPQ (Broadbent et al, 2006) was designed as a short and simple measure of assessing illness representations. The Brief IPQ has reduced the domains of the IPQ-R to just nine questions with one question assessing each illness representation of consequences, timeline, personal control, treatment control, identity, coherence and cause. Emotional responses are divided into emotions and concerns about the illness. Unlike the IPQ and IPQ-R which use a Likert scale, the Brief IPQ assesses perceptions on a 0-12 continuous linear scale. For example, *'how much control do you think you have over your illness'*, where 0 = absolutely no control and 12 = extreme amount of control. Assessment of the causal domain is by an open question asking respondents to list the three most important causes for them. Data were collected from six illness groups to evaluate the psychometric properties of the questionnaire. Analysis showed good test-retest reliability in a renal disease group at three and six weeks. Concurrent validity with the IPQ-R was also established. Discriminant validity was demonstrated by the ability to differentiate between different illnesses. Predictive validity was established in the MI group in terms of a number of recovery outcomes such as return to work.

The authors suggest that the Brief IPQ may be used in preference to the IPQ or IPQ-R in elderly or very ill patients or in those with more limited reading and writing ability. They

advocate its use where illness representations are only one of a series of measurements in large, population-based studies or where repeated measures are required. In this way, the burden on the patient is reduced. However, Broadbent et al (2006) recognise that the IPQ-R may be preferable where the identity domain is important. In addition, the Brief IPQ does not assess cyclical or episodic timeline beliefs which may make it less useful in chronic illnesses. Although patients with heart failure tend to be elderly with limited functional ability, given the nature of the illness in terms of the similarity between symptoms and the effects of medication and the prevalence of co-morbidities, the Brief IPQ may be less preferable than the IPQ-R in assessing illness identity in this population.

The IPQ, IPQ-R and Brief IPQ have been developed as general questionnaires which are not illness-specific. The authors suggest that researchers adapt the scales to particular illness populations, as is the intention in this study. At the most superficial level this could be by simply changing the word 'illness' to a specific named disease such as 'asthma'. However, Moss-Morris et al (2002, p.14) argue that more fundamental adaptations may be necessary in different illness groups due to the *'powerful influence of unique characteristics of an illness'*. They argue that causal and identity domains will be particularly unique.

The IPQ, IPQ-R and Brief IPQ have been adapted for use in a number of specific illnesses and brought together on a website devoted to their application ([www.uib.no/ipq](http://www.uib.no/ipq)). The IPQ appears in eight languages and has been adapted for use in four illness groups. The IPQ-R has been translated into seventeen languages and adapted for use in thirteen illness groups. The Brief IPQ has similarly been translated into twenty-two languages. Over one hundred publications using the IPQ or IPQ-R are cited on the website. On further examination of the adapted versions of the questionnaires, they have either been translated without further amendment or the wording has been changed from 'illness' to the specific condition.

The HIV and Hypertension versions have, however, undergone more extensive changes. In the HIV scale ([www.uib.no/ipq](http://www.uib.no/ipq)), there are additional timeline beliefs which explore perceptions of the illness trajectory or whether the illness is likely to get better, worse or stay the same over time, and the expected rate of improvement or deterioration. For example, *'I expect my illness to get worse quickly'*, and *'I expect my state of health to remain how it is for the foreseeable future'*. These items were included following qualitative interviews with HIV patients. In relation to symptoms, additional items are included which are illness specific, for example, night sweats. The severity of symptoms is also assessed on a 5-point scale from *'very mild'* to *'very severe'*. In an extension of the



CSM, the HIV scale also assesses treatment beliefs. For example, *'are you currently experiencing this symptom as a result of taking combination therapy?'* Similarly, the Hypertension scale ([www.uib.no/ipq](http://www.uib.no/ipq)) combines illness representations with treatment beliefs. For example, *'my treatment will be effective in curing my high blood pressure'*. In a complex exploration of symptom beliefs, respondents are asked whether they have experienced a specific symptom, whether this symptom is related to their high blood pressure or whether the symptom is related to the medication.

The HIV and Hypertension scales are consistent with the CSM but have been adapted to specific conditions following a qualitative exploration of beliefs in individual illness populations. The expansion of the CSM into treatment beliefs allows for the exploration of these beliefs and their relationship to medication regimes.

No studies have been found which use a version of the IPQ-R adapted for use in heart failure, although the IPQ-R has been used unchanged in this population (Morgan, 2008; Cherrington et al, 2006; Voelmeck 2006.) The Survey of Illness Beliefs in Heart Failure Tool (SIBHFT) (Albert and Zeller, 2007) is illness-specific, and has a stated purpose of measuring the accuracy and certainty of illness beliefs in patients with heart failure, rather than measuring illness beliefs *per se*. Developed in the US using the CSM as the theoretical framework, this 14-item scale includes 'accurate' and 'inaccurate beliefs' about heart failure as determined by cardiology medical consultants and specialist nurses. An example of an accurate belief is, *'heart failure is a threat to my health'* and an inaccurate belief, *'heart failure requires me to drink fluids, especially when I am thirsty'*. Respondents are asked to rate their agreement or disagreement with each statement on a 4-point Likert scale. The illness representation of causation is not assessed. Tested on a sample of 104 hospitalised heart failure patients, internal consistency of the scale as a whole was good,  $\alpha = 0.73$ . Factor analysis supported a 2-factor structure of accurate and inaccurate illness beliefs. However, a number of theoretical difficulties exist, for example, the statement *'heart failure can be cured with drugs and other therapies'* is identified as a belief about consequences when it appears to be more related to the dimension of treatment control. Similarly, the statement *'heart failure may improve with drugs and a lot of time'* is described as a consequence rather than a treatment control or timeline item. Furthermore, since only specific, inaccurate beliefs are included, other misconceptions which might exist are not assessed. This may be especially problematic as the scale was developed by experts rather than from a lay perspective. It is quite possible that individuals with heart failure have different beliefs and misconceptions than those envisaged by health professionals, as suggested by Kleinman (1988).

In conclusion, the CSM appears to be a useful framework for examining illness beliefs in heart failure. The IPQ-R has been shown to be a valid and reliable instrument in other illnesses but might need to be adapted for use in heart failure to make it illness-specific. Although a scale exists for measuring illness beliefs in heart failure (the SIBHFT) theoretical difficulties are apparent. Therefore, in this study, an adapted version of the IPQ-R, developed from a patient perspective, is believed to be the most appropriate measure for determining illness representations in a heart failure population.

#### **2.2.4 An extended CSM including treatment beliefs**

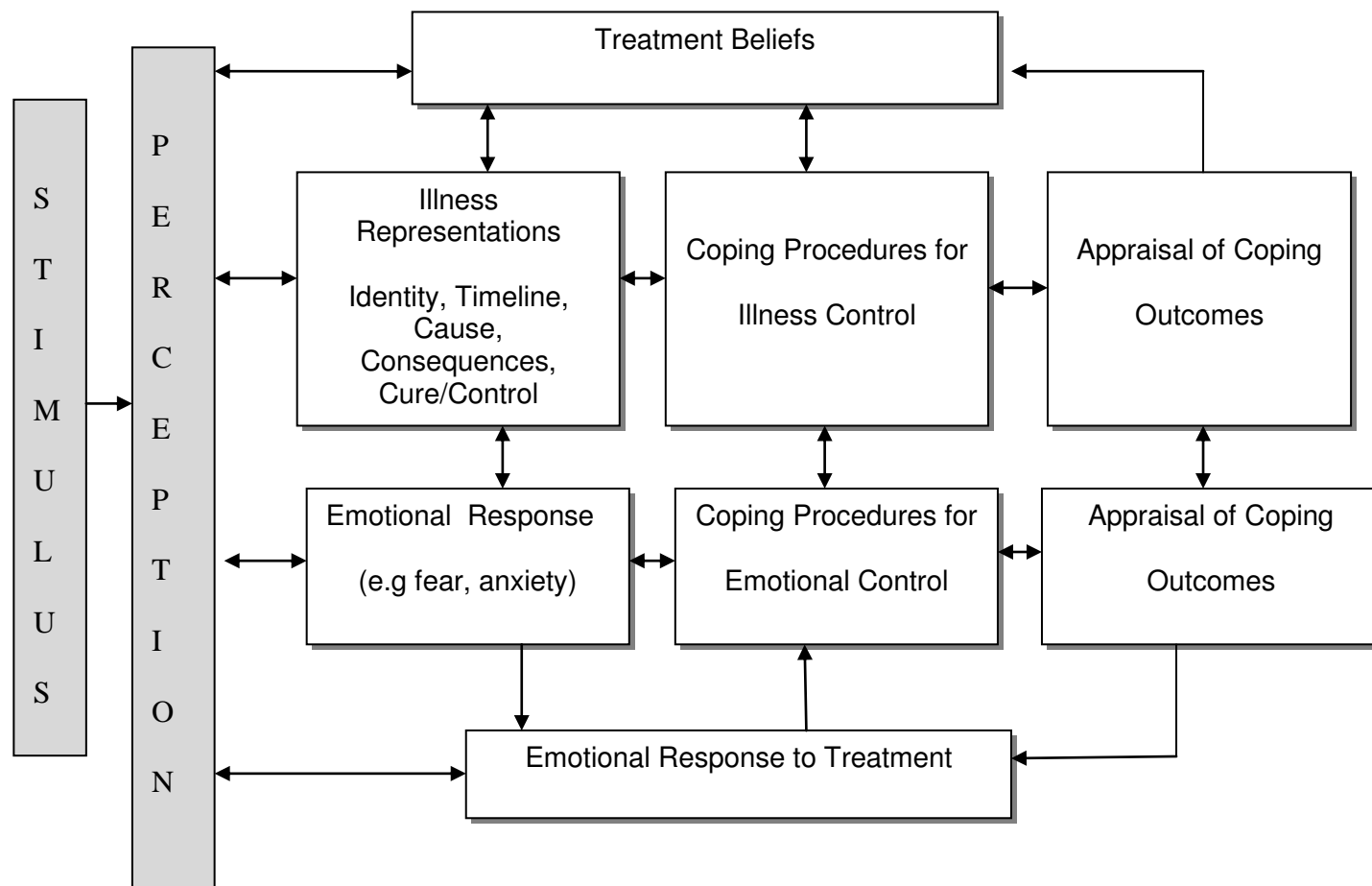
Horne (1997) proposed an extended CSM, incorporating beliefs about treatment as well as illness representations since, he argues, coping responses include making decisions about treatment. The assumption is that individuals search for a coherent explanatory model of both the illness and its treatment so that treatment beliefs are consistent with the individuals' representation of illness (Figure 2.2).

According to this model, symptom experiences trigger treatment beliefs as well as illness representations. If symptoms are attributed to the illness, beliefs about the necessity of treatment may be re-enforced; conversely, the belief that symptoms are the effects of medication leads to the development of concerns about the treatment. Parallel processing of cognitive and emotional dimensions occurs so that the belief that medication has damaging effects results in worry and anxiety.

The belief that the illness is cyclical rather than chronic, for example, may result in doubts about the necessity of taking regular medication. Cause and control beliefs are also expected to be important in that a belief that the illness is caused by poor diet for example, and can be controlled by dietary modification may result in low necessity beliefs about medication. Conversely, a belief that the illness has serious consequences may reinforce the necessity of medication. Treatment beliefs are described as influencing adherence to medication which is viewed as a behavioural response. The outcome of these responses is appraised with resulting reinforcement or a change in treatment beliefs and adherence behaviour.

Contextual factors such as social and cultural norms, demographic factors and personality are thought to inform treatment beliefs and adherence behaviour. For example, spousal beliefs about the necessity of medication and their practical support in medication management may influence adherence. In addition, beliefs about medications generally, may inform beliefs about specific medicines. Perceptions of personal sensitivity and susceptibility to side-effects of medication (the sensitive soma) and perceptions of personal resilience or hardiness may also influence treatment beliefs (Horne, 1997).

Figure 2.2 An Extended CSM, Incorporating Treatment Beliefs (Horne, 1997)



### 2.2.5 The measurement of treatment beliefs

The nature of lay beliefs about treatment was explored by Fallsberg (1991). Three sets of beliefs about medication were identified, a beneficial view of medication in promoting health, a harmful view of medicines as essentially 'poisons' and a dual nature with medication having the potential for harm as well as benefit – a 'double-edged sword'. The potential for harm was expressed as fears about addiction and dependence and damaging side-effects either in the short or long-term.

Horne et al (1999) conceptualised these beliefs in a model incorporating beliefs about the necessity of and concerns about medication in a 'necessity-concerns framework'. Beliefs about medication prescribed for a specific illness were differentiated from beliefs held about medicines generally. The 'Beliefs about Medicines Questionnaire' (BMQ) (Horne et al, 1999) developed these core themes into a quantifiable form. The BMQ-Specific scale examines beliefs about medicines prescribed for a specific condition. It consists of two sub-scales, beliefs about the necessity and efficacy of medicines and concerns about their harmful effects. For example, *'my medicines protect me from becoming worse'*, and *'I sometimes worry about the long-term effects of my medicines'*. The BMQ-General scale is also divided into two sub-scales that assess the belief that medicines are generally over-used by doctors and that medicines, in general, are harmful and addictive. For example, *'doctors use too many medicines'* and *'most medicines are addictive'*. Respondents are asked to rate eighteen items across the four sub-scales according to a 5-point Likert scale (Appendix 2).

The BMQ was tested in over 500 patients across six chronic illness groups (asthma, diabetes, renal, cardiac, psychiatric and general medicine). Factor analysis supported the core themes in both the specific and general medication sub-scales. Internal consistency was considered acceptable in most sub-scales ( $\alpha = 0.55$  to  $\alpha = 0.80$ ) in all illness groups with the exception of the general-harm sub-scale. Here, internal consistency was limited in three illness groups with Cronbach's  $\alpha$  ranging from  $\alpha = 0.47$  to  $\alpha = 0.51$ . The authors recommend that the general-harm scale is used with caution and that the BMQ-Specific scale can be used separately. Test-retest reliability was confirmed in the asthma sample at two weeks. The BMQ was able to distinguish between the different illnesses (discriminant validity) and was able to predict the outcome measure of adherence to medication using the Reported Adherence to Medication (RAM) scale.

The authors conclude that the BMQ can be adapted to assess beliefs about medicines for specific conditions or for individual medicines. This can be achieved by changing the

reference statements so that illnesses or medicines can be referred to by name, for example, '*your views about medicines prescribed for your heart failure*' or '*your views about your beta-blockers*'. Additional items have been added to the specific-concerns sub-scale based on qualitative findings in some illnesses. For example, the belief that regular use of analgesics will make them less effective in the future has been added to an analgesia version of the BMQ (Gill and Williams, 2001).

The relationship between necessity and concern was further developed by Horne and Weinman (1999) where it was hypothesised that a cost-benefit analysis might be taking place in which strong perceptions of need might override perceptions of concern. Similarly, low concern might lead to non-adherence if necessity beliefs are also low. A necessity-concerns differential was devised by subtracting concerns from necessity scores. While the authors acknowledge methodological difficulties, in that the score on one scale does not necessarily correspond to the score on the other, the necessity-concerns differential was a better predictor of adherence than either an isolated necessity or concerns score (Horne and Weinman, 1999).

Other measures have been developed to assess beliefs about medication. Figueiras et al (2009) developed the 'Generic Medicines Scale' which assesses lay beliefs about generic versus branded medicines. Instruments measuring treatment beliefs in relation to specific illnesses or medicines have also been developed, for example, Davidson and Fristad (2006) developed the 'Treatment Beliefs Questionnaire' to measure beliefs about mood disorders and medication in children and their parents.

In heart failure, Bennett et al (1997) developed the 'Beliefs about Medication Compliance Scale' based on the Health Belief Model (Rosenstock, 1974). This was developed to assess the benefits of and barriers to medication compliance rather than beliefs about medication. Although individual items such as '*taking my water tablets helps me breathe more easily*' and '*taking water tablets is unpleasant*' are seemingly related to necessity and concern beliefs, the scale assesses a different, though probably related construct of beliefs about compliance. For this reason, the BMQ is considered to be more useful in assessing treatment beliefs than the Beliefs about Medication Compliance Scale, in this study.

## **2.2.6 Illness and treatment beliefs in heart failure**

A number of qualitative studies have explored lay beliefs and the experience of heart failure. Mahoney (2001) interviewed 28 patients with heart failure and their families in the US, using an ethnographic approach. Living with heart failure was viewed as a disruption

to the normal life course causing disorder on physical, emotional, social, economic and spiritual levels. Viewing the illness in this way is consistent with the concept of biographical disruption suggested by Bury (1982). According to Mahoney (2001), lack of coherence or the illness not making sense often followed such a disruption which echoes the importance of illness coherence as assessed in the IPQ-R (Moss-Morris et al, 2002). The lived experience of heart failure was characterised by struggling, participating in partnerships, finding purpose and meaning in the illness experience and surrendering to, or coming to terms with the illness. The need to generate linguistic codes or labels, as suggested by Leventhal et al (1997), was also apparent in this study where participants attempted to reconcile their own beliefs about the labelling of the illness with medical terminology. For example, 'an asthmatic heart' is described. Misconceptions were found in relation to the control of symptoms. For example, one participant describes sleeping on her stomach rather than on her back so that she would not drown. The cause of the illness was frequently attributed to God's will. The illness representations of identity, cause, and controllability according to the CSM were, therefore, articulated in this study, further supporting the applicability of this model in heart failure.

Zambroski (2003) interviewed eleven patients with heart failure. In terms of the illness identity, the terms 'wind' and 'water' were frequently used by participants to describe problems of increased fluid and a feeling of being underwater or drowning. Terms such as gasping, puffing and blowing were described in relation to breathlessness. Continuing this metaphor, the author categorised the experience of living with heart failure as periods of turbulence, navigation and finding safe harbour. This supports the view that the illness can be described in terms of physical, emotional and social disruption (Bury, 1982).

Illness beliefs and behaviour were influenced by ethnicity and culture in a study by Pattenden et al (2007). Here, 36 patients with heart failure and twenty family caregivers in the UK were interviewed. Differences were found in the way participants of South Asian origin described their heart failure. In this ethnic group, control of the illness was believed to be achieved by a combination of medication and prayer. Cleanliness and mobility were seen as important aspects of care as they related to religious practices. The findings of this study suggest that beliefs and behaviour are culturally influenced, as envisaged by Cameron and Moss-Morris (2004), Leventhal et al (1997) and Kleinman (1988).

Jeon et al (2010) carried out a systematic, narrative review of qualitative studies concerning the experience of living with heart failure. The studies reviewed revealed that social isolation arising from lifestyle changes, medication regimes, the effects of

medication and physical restrictions due to breathlessness and tiredness were common. Strong emotions such as fear, distress and uncertainty was a key feature of living with the illness. A sense of control was also deemed important with loss of control connected with deterioration in symptoms, loss of independence and lifestyle restrictions. The most common coping strategies were sharing the illness experience through accepting practical and emotional help and adjusting to changing circumstances by accepting physical limitations and adjusting activities accordingly.

Using the CSM as the theoretical framework, Horowitz et al (2004) carried out semi-structured interviews with nineteen patients with heart failure in the US. They found that participants lacked a coherent model of heart failure and had inadequate knowledge about the causes, symptoms and the consequences of their illness. They often did not connect symptoms of heart failure to the condition. While most described fluid build-up, few labelled this as related to their heart and could not explain what caused their condition or its symptoms. Others attributed symptoms to conditions such as asthma or external causes such as stress. In relation to timeline, participants described an acute condition with few serious consequences. They did not recognise that their symptoms worsened over time and did not manage symptoms effectively so were unable to prevent acute exacerbations.

A small number of studies have published quantitative findings on illness representations in heart failure. Albert and Zellar (2007) used the SIBHFT to measure illness beliefs in 104 hospitalised patients in the US and, like Horowitz et al (2004), found that patients held inaccurate beliefs about heart failure and had little perceived control over their illness. In contrast, Voelmeck (2006), using the IPQ-R, studied 98 patients with heart failure in the US and found that the illness was believed to be chronic with serious consequences. The belief that the illness could be controlled by personal and treatment measures was also found.

Cherrington et al (2006) also used the IPQ-R in a small study of 22 patients with heart failure, in the US. For the identity domain, participants experienced an average of 6.6 symptoms which they believed were related to their heart failure. No causal factors could be identified. As the IPQ-R was used without making it specific to heart failure, the author acknowledges the need to revise the causal sub-scale to more accurately reflect the aetiologies in heart failure. The identity sub-scale may also require amendment for the same reason. Consistent with the findings of Voelmeck (2006), a belief in a chronic timeline was found. There was a belief in the illness having serious consequences with a

high degree of personal and treatment control reported. Illness coherence was also high and there was a lack of a negative emotional effect. Morgan (2008), using the IPQ-R, found few symptoms were attributed to heart failure, a belief that the illness was a long-term condition with serious consequences but one which could be controlled personally and through the use of medication. The illness was most commonly attributed to hereditary factors but stress and worry and ageing were also identified as causal factors. Few negative emotions were described. Hallas et al (2010) demonstrated the link between illness beliefs and emotional response in that those patients with more negative beliefs about the consequences of their illness and with less perceived control showed greater levels of depression and anxiety.

Only three studies have been found which address treatment beliefs in heart failure. Ekman et al (2006) studied the medication beliefs of 302 Swedish heart failure patients as part of a large, 5-year randomised controlled drug trial. It was found that 94% of the sample believed that the study medication would make them feel better compared to 82% believing that their regular heart failure medication would make them feel better. 69% of patients were knowledgeable about the names of their medication but only 16% of patients were aware of the need to take medication for the rest of their lives. Since this sample was drawn from patients undergoing a clinical trial, it might be expected that beliefs about the efficacy of medication and medication knowledge were high which may not necessarily be the case in a general heart failure population. De Smedt et al (2009) studied the perception of adverse effects of heart failure medication in a sample of 680 hospitalised patients in Sweden; 17% reported at least one perceived adverse effect such as nausea, dizziness, itching or a rash.

In a study by Rogers et al (2002), 27 heart failure patients were interviewed to examine their perceptions of symptoms and drug therapy. These authors found that patients had little understanding of what medications were intended to achieve. Patients expressed concerns about higher doses and interactions between drugs, especially after reading the patient information leaflets included in the drug packaging. Patients reported nineteen different symptoms which were attributed to old age, symptoms of heart failure or side-effects of medication. Distinguishing the effects of medication and symptoms of the condition was especially problematic. This applied particularly to tiredness and a depressed or anxious mood. The authors assert that this lack of understanding posed a number of problems for patients in interpreting the significance of changing symptoms.



In conclusion, heart failure has a significant impact on physical, social and emotional well-being and lay beliefs may be incongruent with the biomedical model. Using the CSM, there are conflicting findings between studies by Horowitz et al (2004) and Albert and Zellar (2007), who describe an acute or episodic model of the illness and a number of misconceptions, and the findings of Voelmeck (2006), Cherrington et al (2006) and Morgan (2008) who, using the IPQ-R, describe a chronic timeline and fewer misconceptions. However, it should be noted that these studies were conducted in the US and Republic of Ireland in relatively small samples in some cases, which may limit the generalisability of the findings. Data on treatment beliefs in heart failure is scarce, although it is suggested that there are strong beliefs about the necessity of medication but also concerns about its effects. Differentiating symptoms from the effects of medication may also be difficult for some patients.

## **2.3 SELF-CARE POLICY AND PRACTICE**

This section discusses self-care in heart failure within the context of current UK health and social care policy. Policy initiatives are discussed and the definition of self-care as used in this thesis is re-stated. The nature, extent and measurement of self-care in heart failure are discussed. Finally, the factors influencing self-care are examined.

### **2.3.1 Health and social care policy**

The concept of self-care in health and social care policy can be traced back to 2000 with the publication of the NHS Plan (DH, 2000b). Here, self-care was described as one of the '*key building blocks for a patient-centred health service*' (DH, 2000b, p.3). Since 2000, a number of publications have driven the self-care agenda. In 'The Expert Patient: A new approach to chronic disease management for the 21<sup>st</sup> century' (DH, 2001), the belief that patients could become experts in their own illness was articulated. 'Expert Patient Programmes' (EPPs) were described as a way of enabling people with long-term conditions, such as heart failure, to self-care. In 2005, 'Self-Care – A Real Choice' was published which defined self-care in operational terms (DH, 2005b). In this year, the National Service Framework (NSF) for long-term conditions was also published (DH, 2005a). Here, supporting self-care was identified as a core quality requirement.

The publication of 'Supporting people with long-term conditions to self-care: A guide to developing local strategies and good practice' (DH, 2006a) brought together a number of policy strands to embed self-care in health and social care practice. The white paper, 'Our health, our care, our say' (DH, 2006b), suggested that people with long-term conditions wanted more control over their care and led to the launch of 'Your health, your way – a

guide to long-term conditions and self-care' (DH, 2008). The central focus was to promote discussion between health and social care professionals and individuals about the support and information available to enable self-care in the form of a 'Patients' Prospectus'. November 2009 saw the first national 'Self-Care Week' which aimed to raise awareness of self-care, highlight the information available and encourage patients with long-term conditions to discuss a personal care plan with their healthcare provider.

It is anticipated that voluntary or third sector organisations will play an increasing role in meeting the increased demand for self-care support (DH, 2010a), illustrating the coalition government's vision of a 'Big Society'. Most recently, the new Secretary of State for Health, described patients not as beneficiaries of care but as participants in shared decision-making (DH, 2010b). The recently published strategy for the NHS (DH, 2010c) emphasises an information revolution with greater choice and control for patients, suggesting an ongoing commitment to the principle of self-care.

The DH (2006a) defines self-care as:

*'the activities that enable people to deal with the impact of a long-term condition on their daily lives, dealing with the emotional changes, adherence to treatment regimes, and maintaining those things that are important to them – work, socialising, family'*  
(DH, 2006a, p.2)

This broad definition of self-care is used in this thesis as it recognises emotional and social dimensions of self-care, rather than simply focusing on compliance or adherence to professionally determined medication and lifestyle regimes. The term 'self-management' is also used in the literature although this has predominantly been applied to education such as the Expert Patient Programme (EPP) (DH, 2001). Self-care has been described as an umbrella term which includes self-management (DH, 2009).

Central to the concept of self-care is the belief that patients with long-term conditions, through their experience, can become empowered to increase their knowledge and become key decision makers rather than passive recipients of care. It is suggested that patients expect to play a much greater part in managing their illness (DH, 2001). The concept of empowerment is explicit in self-care and requires a shift in the balance of power from health professionals to patients. Nettleton (2006) defines empowerment as *'the process of enabling people to have the power to take action to control and enhance their lives'* (Nettleton, 2006, p.239). The DH acknowledges that promoting self-care

*'requires a radical shift in the balance of power, with the patient at the centre'* (DH, 2006a, p.12).

Although 82% of people with a long-term condition said they played an active role in caring for themselves (DH, 2007), levels of self-care were not consistent across different age groups, with younger people and those over 85 years of age described as less active in self-care. Deprived and minority ethnic groups were also less likely to engage in self-care. Those groups least active in self-care also lacked confidence in their knowledge and understanding of self-care (DH, 2005c).

The benefits perceived for effective self-care are considered to be numerous and include, rather ambitiously, better health and well-being for patients, reduced perceived severity of symptoms, improved adherence to medication, reduced need for emergency health and social services, prevention of unnecessary hospital admissions, better planned and co-ordinated care, greater confidence and a sense of control and better mental health with a reduced incidence of depression (DH, 2006a). In addition, a number of studies have demonstrated potential service benefits including a 40% reduction in GP visits, a 17% reduction in outpatient appointments, a 50% reduction in visits to A&E and reduced drug expenditure (DH, 2007).

However, in realising these benefits, a number of factors are recognised which may affect self-care. These include perceived or actual illness severity, the nature of the condition, the effect of symptoms, the short, medium and long-term impact of the condition on the individual's ability to undertake normal activities of daily living, the person's beliefs, understanding and expectations surrounding their condition, patients' morale and mental health and the perceived role of health and social care services in providing care, cure or support (DH, 2006a).

Hence, five key areas of support have been identified as essential to achieving the aim of effective self-care. These are information about the condition, services to support healthy lifestyle choices such as smoking cessation, skills training courses such as EPP, support networks and tools and equipment. Information prescriptions have been developed as a way to provide people with long-term conditions with individually tailored information on their condition and available services (DH, 2009b).

The EPP (DH, 2001) has been developed as a formal education programme which aims to provide the patient with the skills necessary for self-care. Implemented widely in the UK, the EPP is highly structured and lay-led and may be generic or illness specific. For

example, programmes exist in diabetes, arthritis and asthma care (Wilson and Mayor, 2005). The EPP is based on the Chronic Disease Self-Management Programme (CDSMP) developed at Stanford University based on the work of Kate Lorig. In this author's original study, the implementation of an arthritis self-management programme (ASMP) led to benefits in health outcomes such as reduced pain (Lorig et al, 1985). Furthermore, patients with reduced pain also reported greater control over their illness, leading to the hypothesis that changes in self-efficacy (Bandura, 1977) were partly responsible for the improvements reported in the ASMP (Lorig et al, 1989). A later version of the ASMP, incorporating efficacy-enhancing strategies, resulted in further improved health outcomes which were retained over time, including a reduced number of hospital visits (Lorig et al, 1993).

In heart failure, Smeulders et al (2009) considered the impact of a self-management group programme on health behaviour and healthcare utilization among 317 heart failure patients in the Netherlands. They found that patients in the intervention group spent more time in physical activities such as aerobic, stretching and strength exercises, sports, and gardening, directly after the programme and at 6 months follow-up. However, the programme had no effect on drinking or smoking behaviour, body mass, or healthcare utilization. These authors conclude that there is limited evidence of a beneficial effect of the CDSMP on some health behaviours and healthcare utilization in this population.

In addition to policy relating to the general principles of self-care, NICE (2009) has issued specific guidance on supporting medication adherence which is an important element of self-care. Non-adherence is described as intentional or unintentional and it is emphasised that non-adherence should not be seen as the patient's problem but rather a fundamental limitation in the delivery of healthcare through a failure to fully agree the prescription or provide ongoing patient support. Unintentional non-adherence occurs when the patient wants to follow the agreed treatment but is prevented from doing so by barriers beyond their control such as difficulty in understanding the instructions, inability to pay for treatment or simply forgetting to take medication. Intentional non-adherence occurs when the patient decides not to follow the treatment recommendations. Here, patient beliefs and preferences are seen as important in understanding the motivation to start and continue with treatment. The necessity-concerns framework (Horne and Weinman, 1999) is explicitly applied in that a key principle is *'to be aware that patients' concerns about medicines and whether they need them, affect how and whether they take their prescribed medicines'* (NICE, 2009, p.8). Healthcare providers are asked to assess, regularly review and address medication knowledge, concerns and necessity beliefs. A recommendation

by NICE (2009) is the need for further research to determine the most clinically and cost-effective methods for identifying and addressing beliefs and concerns about medication that influence adherence.

In conclusion, a definition of self-care has been given which encompasses emotional and social well-being as well as adherence to medication and lifestyle advice. Self-care has been presented as a cornerstone of health and social care policy in long-term conditions such as heart failure. There are a number of perceived benefits of self-care for the individual, their families and health and social care service. Although self-care is believed to be high in patients with long-term conditions, it is recognised that those in older age groups, ethnic minority and deprived groups may be less effective in engaging in self-care. Five key areas have been targeted to support self-care in long-term conditions, most importantly support for enhancing knowledge and skills. NICE (2009) has issued clinical guidelines relating to medication adherence in which the identification of treatment beliefs, specifically necessity and concern beliefs is viewed as important in the assessment of adherence. The following section reviews the literature in relation to the specific nature and extent of self-care, including medication adherence, in heart failure.

### **2.3.2 The nature and extent of self-care in heart failure**

A framework for conceptualising self-care in heart failure has been proposed by Dickson et al (2006) who describe self-care as a naturalistic decision-making process involving a choice of behaviours that maintain physiological stability (self-care maintenance) and recognising and responding to symptoms when they occur (self-care management). Self-care maintenance includes adherence to medication and lifestyle advice. However, if the broad definition of self-care is used according to the DH (2006a), self-care maintenance also includes individuals maintaining those things that are important to them such as work, leisure activities and social networks. Self-care management is seen as a process initiated by symptom recognition and evaluation. Table 2.4 summarises self-care maintenance and self-care management behaviours in heart failure.

**Table 2.4      Self-Care Maintenance and Management Behaviours**

<b>Self-Care Maintenance</b>	<b>Self-Care Management</b>
Taking medications as prescribed	Weighing oneself regularly
Adhering to a low sodium diet	Symptom recognition and evaluation
Maintaining an ideal body weight	Managing symptoms
Limiting alcohol intake	Seeking help and advice
Restricting fluid intake	
Taking regular exercise	
Flu and Pneumonia immunisation	
Smoking cessation	
Based on Riegel et al (2009a); Dickson et al (2006); Jaarsma et al (2000b)	

The terms compliance, adherence and, less commonly, concordance have been used in studies investigating self-care maintenance behaviour in heart failure. NICE (2009) and Sabate (2003) for the World Health Organisation (WHO), use the term adherence which is defined as:

*‘The extent to which a person’s behaviour – taking medication, following a diet and/or executing lifestyle changes, corresponds with the agreed recommendations from a provider’*  
(Sabate, for the WHO, 2003)

In contrast to compliance, adherence implies a less powerful role for the health professional in that it requires the patients’ agreement to the recommendation (Fraser, 2010). The concept of concordance describes the process by which beliefs are shared and an equal partnership between the individual and health professional is envisaged (DH, 1997). In this study, since self-care is viewed as a behavioural outcome, according to the CSM, the term adherence will be used.

Implicit in this research is the assumption that self-care affects clinical outcomes. However, few studies have conclusively demonstrated such a relationship. De Walt et al (2006) evaluated the effect of a self-care programme designed for heart failure patients with low literacy and found that the intervention group had lower mortality and fewer episodes of hospitalisation. Similar results were found by Lee et al (2007), who investigated the effect of self-management strategies on mortality and rate of hospitalisation and found that those with better self-management had lower mortality and fewer hospital admissions at one year. Falk et al (2009) also investigated self-care and survival in a sample of heart failure patients in Sweden, finding that poor self-care was an independent predicator of risk of death within twelve months, controlling for age and

NYHA classification. Grady (2008) in a literature review investigated the relationship between Health Related Quality of Life (HRQoL) and self-care and reported that whilst most studies suggested an improvement in HRQoL, the results were inconclusive. An American Heart Association (AHA) statement (Riegel et al, 2009a) identifies a need to establish the direct effect of heart failure self-care on clinical outcomes including survival and HRQoL, as an urgent priority.

There are wide variations in the reported extent of self-care in heart failure, especially in relation to medication adherence. The reasons for this are speculative although the different ways in which adherence and self-care are measured is likely to be a significant factor. Studies show that low levels of adherence to some aspect of self-care maintenance in heart failure is prevalent, ranging from 20-65% (Leventhal et al, 2005). Furthermore, self-care management behaviours such as managing and reporting symptoms have been found to be less frequently practised than self-care maintenance behaviours (Artinian et al, 2002).

Using self-report measures, Van de Wal et al (2004) found adherence to medication to be 96%, to diet, 80% and weighing at least once a week, 52%. Albert (2008) found that adherence to ACEI was just 39%. The Carvedilol or Metoprolol European Trial (COMET) (Ekman et al, 2006) estimated a medication adherence rate of 76%. In the Candesartan in Heart Failure: Assessment of Reduction in Mortality and Morbidity (CHARM) trial (Granger et al, 2005), 89% of patients were over 80% adherent. In a review of adherence in the elderly, Van de Wal and Jaarsma (2007) cite rates from 10% to 99%. Adherence to a low sodium diet ranged from 13% to 75% and to a fluid restriction, 23% to 70%. Daily weighing ranged from 14% to 79% adherence. In conclusion, the findings from studies examining the extent of self-care and medication adherence in heart failure appear to be highly variable. The following section critiques the methods that have been used to measure adherence to medication and self-care in heart failure.

### **2.3.3 Measuring medication adherence and self-care**

Medication adherence has been measured directly using a number of seemingly objective measures as well as the more subjective method of self-report. Commonly used measures include pill counts, the rate at which prescriptions are filled out or electronic Medication Event Monitoring Systems (MEMS). Here, the number of times a container is opened is recorded. However, although these methods are considered to be objective, there is no guarantee that medications are actually taken. Self-report measures are

considered to be more subjective and dependent upon accurate recall with some patients being tempted to exaggerate their adherence (Smith et al, 2009).

Several studies have investigated the congruence between different measures of medication adherence in heart failure. Van De Wal and Jaarsma (2007) found a disparity between self-reported adherence to ACEI (99% adherence) and that recorded by MEMS (73%). In contrast, Chung et al (2006a) found broad agreement between self-reported medication adherence and MEMS. Smith et al (2009) aimed to identify a 'gold standard' for measuring medication adherence in a UK population of elderly heart failure patients. Adherence to ACEI and diuretics over a six week period was measured using pill counts, MEMS and a self-report questionnaire. An adherence threshold of  $\geq 80\%$  was set which was considered an acceptable level of adherence. In relation to ACEI, 81% of patients were classified as adherent by self-report, 79% according to pill count but only 20% for electronic monitoring. For diuretics, 55% were classified as adherent by self-report, 63% by pill count and only 11% for electronic monitoring. On further analysis, the pattern of container opening as measured by MEMS was consistent with the use of a dosing aid such as a Dosette® Box where the container was opened weekly to fill the box. The authors conclude that it is not possible to select one method as the 'gold standard' but pill counts and self-report, which were most closely correlated, are the most valid measures of adherence in heart failure.

Adherence to a low salt or sodium diet can be measured using the objective method of urinalysis or self-report. Chung et al (2006b) investigated the ability of patients to accurately measure adherence to a low sodium diet using a combination of these methods. They concluded that patients found it difficult to accurately rate their adherence to a low sodium diet. Lennie et al (2008) also found a disparity between self-reported adherence (75%) compared to urinalysis (25%). These studies, conducted in the US, suggest that it may be more difficult for heart failure patient to accurately assess adherence to a low sodium diet compared to medication. The reasons for this are likely to be complex but may be related to a lack of information of what constitutes a 'low salt' diet and difficulty assessing the sodium content of food, especially that which is pre-prepared or when dining out.

Levels of self-care, including medication adherence have commonly been obtained by self-report questionnaires. Two widely cited examples are the Self-Care of Heart Failure Index (SCHFI) (Riegel et al, 2004) and the European Heart Failure Self-care Behaviour Scale (EHFScBS) (Jaarsma et al, 2003).



The SCHFI (Riegel et al, 2004) was developed in the US to measure self-care maintenance behaviour and the decision-making processes involved in managing the symptoms of heart failure. Developed from the earlier Self-Management of Heart Failure Tool (Riegel et al, 2000), the SCHFI is a self-report measure of fifteen items rated on a 4-point scale. The index is divided into three sub-scales – self-care maintenance in which respondents are asked to rate the frequency of carrying out individual behaviours, for example, *'I weigh myself daily'*; a complex self-care management sub-scale in which respondents are asked if they have had trouble breathing or experienced ankle swelling and if so, how quickly they recognised these as symptoms of heart failure, what remedies they tried, for example, *'taking an extra water pill'*, and how sure they were that the remedy worked (treatment efficacy). The final sub-scale assesses self-confidence (self-efficacy), for example, *'how confident are you that you can evaluate the importance of your symptoms?'* The index was used on 760 patients with heart failure. Reliability of the scale as a whole was described as adequate (Cronbach's  $\alpha = 0.76$ ) although the reliability of the self-care maintenance sub-scale was moderate ( $\alpha = 0.56$ ). Since only the symptoms of trouble breathing and ankle swelling are included, the scale is limited to patients who experience these symptoms. In addition some remedies are not advocated in all patients in the UK, taking an extra diuretic or water tablet, for example. Furthermore, since this index combines both behavioural and psychological processes, it is difficult to determine the relationship between beliefs and behaviour which is the aim of this current study. An update on the SCHFI (version 6) with added maintenance items and a modified response format has been issued (Riegel et al, 2009b), although the internal consistency of the scale is not significantly improved.

The EHFSBS (Jaarsma, et al, 2003) (Appendix 3) was developed and piloted in a number of centres in Sweden and the Netherlands before being tested in 442 patients in Sweden, the Netherlands and Italy. It was developed in English with translation and back translated into Swedish and Dutch. Orem's model of self-care was used as the theoretical framework (Orem, 1995). The scale is a 12-item, self-administered questionnaire in which respondents are asked to rate the extent to which they agree or disagree with statements on a 5-point scale. Designed to measure only behavioural outcomes, the authors recognised a need for the scale to be able to measure the effects of interventions such as education programmes. The scale was developed by healthcare professionals and emphasises self-care maintenance behaviours, for example, *'I restrict my sodium intake'*. Although the scale claims to address healthy functioning and well-being, this is not evident in the questionnaire. In addition, monitoring and responding to symptoms are not differentiated in statements such as *'If my shortness of breath increases, I contact my*

*doctor or nurse*'. Furthermore, factor analysis failed to confirm the theoretically derived dimensions of complying with regimes, asking for help and adapting activities. Items loaded on more than one factor or could not be theoretically identified as separate factors. Internal consistency of the individual sub-scales was limited ranging from  $\alpha = 0.46 - 0.67$ . In light of this analysis, the use of a total self-care score is advocated by the authors. Internal consistency of the questionnaire as a whole was good at  $\alpha = 0.81$ . The authors conclude that although useful for research purposes, the scale requires additional testing before it can be used in clinical practice. The questionnaire has since been revised into a 9-item scale and further tested (Jaarsma et al, 2009). Internal consistency was calculated as  $\alpha = 0.80$ , with one reliable sub-scale identified (consulting behaviour).

The EHFSBS has been translated into fourteen languages. A Japanese version (Kato et al, 2007), demonstrated acceptable but weaker internal consistency compared to the original questionnaire ( $\alpha = 0.71$ ). Shuldham et al (2007) tested the scale in 183 patients with heart failure in England and found the scale to be moderately reliable in this sample ( $\alpha = 0.69$ ). Again, principal components analysis did not confirm the theoretically derived factor structure. Furthermore, no correlations were found between the EHFSBS, the SCHFI and the Minnesota Living with Heart Failure Questionnaire (MLHFQ) (Riegel et al, 2002; Rector et al, 1997), a health-related quality of life (HRQoL) measure, suggesting that concurrent validity of the EHFSBS has not been established, which may limit its use in practice.

In conclusion, a number of methods exist for measuring medication adherence such as pill counts, MEMS and self-report, although no gold standard exists between these methods. Adherence to a low salt diet may be more difficult to determine by self-report. In terms of self-care, the SCHFI (Riegel et al, 2004), though a valid and reliable measure, addresses the decision-making process of self-care not just the behaviours carried out by individuals. As such, its use is limited in determining the relationship between beliefs and behaviour. The EHFSBS (Jaarsma, et al, 2003) does assess behaviour, though emphasises self-care maintenance or adherence behaviours. Factor analysis failed to confirm the theoretically derived constructs which made up self-care and the translated English version was less reliable than the original, Swedish version, suggesting a need for further exploration of this scale in a UK population.

## **2.4 FACTORS INFLUENCING SELF-CARE IN HEART FAILURE**

The WHO (Sabate, 2003) developed a multi-dimensional model of factors influencing adherence behaviour in long-term conditions. Although devised as a framework for

adherence, this model is also useful for conceptualising factors influencing self-care. Five main influences are identified - socio-economic, healthcare system, condition, treatment and patient-related factors (Table 2.5).

**Table 2.5**      **Summary of Factors Influencing Self-Care in Heart Failure**

<b>Socio-economic</b>	<b>Healthcare system</b>	<b>Condition-related</b>	<b>Treatment-related</b>	<b>Patient-related</b>
Education	Patient support services	Symptom severity	Effectiveness of treatment	Age
Financial constraints	Patient-Provider relationship	Functional ability	Side-effects	Gender
Level of social support	Provider knowledge and skills	Presence of co-morbidities	Complexity of regime	Knowledge
Culture	Availability of resources	Experience	Changes in regime	Ability
		Cognitive ability		Beliefs, values
				Motivation
				Personality
				Self-efficacy

Based on Leventhal et al (2005) and Sabate (2003).

Many studies have considered the influence of these factors on self-care in heart failure. Socio-economic status including level of education, financial constraints, social support and culture, have been highlighted as influencing factors. Low socio-economic status and educational levels have been found to be important factors relating to non-adherence and poor self-care (Wu et al, 2007; Gary, 2006; Van der Wal et al, 2006). Supporting this, a higher level of education was found to be a significant predictor of adherence in studies by Rockwell and Riegel (2001) and Evangelista and Dracup (2000). This may be due, perhaps, to better health literacy in terms of understanding the illness, knowledge of lifestyle factors and an enhanced ability to manage complex treatment regimes.

Financial constraints due to the cost of medication have been identified as a barrier to adherence (Wu et al, 2008; Horowitz et al 2004; Evangelista et al, 2003). However, these studies were conducted in the US and generally relate to a lack of medical insurance with resulting increased personal costs of medication. Further research is needed to determine whether the cost of medication significantly influences adherence to heart failure medication in a UK healthcare setting. Since most research has been carried out on retired, elderly patients, little is known about the self-care behaviour of employed people. A number of studies suggest that self-care is limited in those who are employed (Kato et al, 2009; Dickson et al, 2008; Dickson et al, 2007a; Kato et al, 2007). It is suggested that

this may be due to better physical functioning and reduced severity of illness and symptom burden which may act to reduce the motivation to self-care.

Social support has been found to be significant factor influencing self-care in many studies (Dunbar et al, 2008; Wu et al 2008; Riegel et al, 2007a; Ortega-Gutierrez et al 2006; Schnell et al, 2006; Scotto, 2005; Artininan et al, 2002; Ni et al, 1999). Chung et al (2006a) investigated the impact of marital status on medication adherence and found that married patients had substantially better adherence than those living alone. Patients with a spouse took more doses, understood the importance of taking medications on time and were more knowledgeable about names and doses. Sebern and Riegel (2009) found that shared communication and decision-making correlated with high levels of self-care. The nature of this support has been described in terms of practical assistance with medication management by giving partners their tablets at prescribed times (Stromberg et al, 1999), or collecting medications from the pharmacy and filling Dosette® Boxes (Wu et al, 2007). These authors conclude that without the active engagement of family members, some patients would have difficulty adhering to their medication regime. In contrast, Evangelista et al (2001) found no correlation between social support and adherence to medication and lifestyle behaviours which, it was suggested, was due to the high levels of social support reported in this sample. In relation to a low sodium diet, Chung et al (2009) found that adherence was improved in those where a spouse or family member also followed the diet.

There is limited evidence on the influence of culture on self-care in heart failure. Wu et al (2007) and Riegel et al (2006) found that self-care practice amongst minority ethnic groups in the US, was poor compared to other groups, even when controlling for other socio-demographic factors. Riegel et al (2007) compared self-care in developed countries (the US and Australia) and developing countries (Mexico and Thailand) and found that self-care was highest in the Australian population and lowest in the Thailand population. No reasons are given to explain this except to suggest that further work is needed to determine the influence of culture on self-care. In contrast, Hebert et al (2010) found no difference in terms of adherence to heart failure medication between Hispanic, White and Black patients in the US.

In summary, socio-economic factors, especially levels of social support are believed to be significant predictors of self-care in heart failure. However, these studies were conducted outside the UK so it is unclear whether these findings can be applied to a UK healthcare setting.

Considering healthcare system-related factors, support from healthcare providers has been found to enable self-care in a number of studies (Wu et al, 2008; Dickson et al, 2006; Schnell et al, 2006; Leventhal et al, 2005; Scotto, 2005; Stromberg et al, 1999). This was due to positive relationships between patients and healthcare providers involving trust, professional knowledge and skill and time for consultations. Enabling skill development was also seen as important. Dissatisfaction with care and lack of physician support was detrimental to self-care in a study by Riegel and Carlson (2002). Though not explicitly stated in these studies, it seems likely that healthcare system-factors are most likely to be related to the self-care practice of seeking help and advice in response to deteriorating symptoms.

A number of factors relating to the illness have been described as influencing self-care. These include the severity of symptoms and related functional ability, level of experience, prior hospitalisation, the presence of co-morbidities and cognitive functioning. Severity of symptoms and functional ability, as measured by the NYHA Functional Classification (NYHA, 1984), have been found to be important predictors of self-care in studies by Wu et al (2007) and Rockwell and Riegel (2001), with those patients with the most severe symptoms and limited functional ability having poorer self-care. However, this is more complex than it at first seems as poor functional ability may also be a motivating factor to self-care (Dickson et al, 2008). Hence, a balance exists between the motivation to self-care and the ability to carry out self-care practices such as monitoring and managing symptoms. Prior experience of hospitalisation also seems to motivate individuals to self-care as those with previous admissions were found to be more likely to care for themselves effectively in a study by Carlson et al (2001), presumably in an effort to avoid future hospitalisations. Similarly, level of experience of heart failure or time since diagnosis may be important in determining self-care ability as it is suggested that those with most experience of the illness have an enhanced ability to recognise changing symptoms and use tried and tested strategies to alleviate symptoms (Carlson et al, 2001).

The presence of co-morbidities, especially if symptoms are similar to those of heart failure, makes the recognition and subsequent management of symptoms difficult for some patients. Chriss et al (2004) found that those with less co-morbidity had enhanced self-care. Given the prevalence of co-morbidities in heart failure, especially amongst older age groups, this suggests that many patients will experience some difficulty in recognising and managing symptoms.

Depression is a prevalent condition in patients with heart failure and can be considered a co-morbidity or an effect of the illness. It is suggested that at least 11% of ambulatory patients and over 50% of hospitalised patients with heart failure are depressed (Leventhal et al, 2005). Depression has been linked to poor self-care in studies by Holzapfel et al (2009), Riegel et al, (2007b), Dickson et al (2006) and Lesman-Leegte et al (2006). Non-adherence is reportedly three times higher in depressed patients compared to those who are not depressed (DiMatteo et al, 2000). It seems likely that the motivation and ability to self-care is more limited in depressed patients so making it important that depression is diagnosed and treated in this population.

Self-management requires that patients make decisions and take actions in response to symptoms. Cognitive deficits in heart failure are well documented (Nicholson, 2007; Bennet and Sauve, 2003; Ekman et al, 1998) with estimates of the prevalence of impairment between 30-50% (Leventhal et al, 2005). Wolfe et al (2005) found specific cognitive deficits in terms of memory, attention and executive functioning which were not related to illness severity. Such deficits may impair the perception and interpretation of symptoms and the reasoning ability required for self-management. This is supported by Dickson et al (2007b), who found a correlation between impaired cognition and individuals inconsistently demonstrating effective self-care. Similarly, Cameron et al (2010) found poorer self-management in those with mild cognitive impairment. Paroxysmal nocturnal dyspnoea, common in heart failure, deprives the body of sleep and may further impair cognitive functioning and decision-making ability (Trupp and Corwin, 2008). Perhaps as a result, the symptom of daytime sleepiness has also been linked to poor self-care (Riegel et al, 2009c).

Adherence to medication has been linked to treatment-related factors such as the effects of medication, complexity of the regime and frequent changes to medication. It seems likely that the effects of medication, for example, the need for frequent urination as a result of diuretics, and side-effects of medication, such as dizziness, may reduce medication adherence (Cowie et al, 1999). The complexity of the treatment regime as indicated by a high number of administration times, for example, has been shown to decrease medication adherence (George and Shalansky, 2007; Van der Wal and Jaarsma, 2007; Riegel and Carlson, 2002). Furthermore, it can reasonably be assumed that the practice of up-titration of heart failure medication, that is increasing the dose to a target level, increases the day-to-day complexity of the regime with perhaps detrimental effects on adherence.

Individual patient characteristics have a role in self-care. Gender may influence behaviour although there is conflicting evidence. Lee et al (2009) found that gender was not a determinant of any aspect of self-care which is in contrast to the findings of Chung et al (2006b) who found that adherence to a low sodium diet was higher in women who were better able to make dietary decisions, perhaps due to increased knowledge. Conversely, Gary (2006) found that few women followed the recommended sodium restrictions, exercised or weighed themselves daily. However, as this was not a comparative study, it cannot be concluded that gender differences existed. Heo et al (2008) found higher perceived control and greater knowledge were associated with better self-care in men, whilst in women higher self-confidence and poorer functional status correlated with better self-care. It seems that gender differences may operate on factors influencing self-care as well as influencing adherence behaviours, such as diet, directly.

The relationship between age and self-care behaviour is similarly unclear. Chriss et al (2004) and Evangelista et al (2003) found that increasing age was an independent predictor of self-care with elderly patients demonstrating greater adherence to medication, diet and exercise advice than younger patients. In contrast, Cline et al (1999) found that non-adherence to medication was more common in elderly patients who had limited knowledge regarding the names of the medication, their use and dosage. However, in this study it is not clear whether age was an independent predictor of self-care or related to other factors such as the presence of co-morbidities, for example.

Another individual factor thought to influence self-care is knowledge about the medication, the condition and required behaviour. Medication knowledge including the names of the medication, mode and times of administration and the effects has been shown to impact on adherence (Ekman et al, 2006; Toren et al, 2006; Cline et al, 1999). Furthermore, knowledge about the relationship between the illness and medication was found to be important in a study by Wu et al (2008). Here, the ability to connect symptoms and the medications effectiveness in decreasing those symptoms enhanced medication adherence. In relation to lifestyle recommendations, Van der Wal et al (2006) found that patients did not regularly weigh themselves due to lack of knowledge of the reasons for weighing. Similarly, Ni et al (1999) and Riegel and Carlson (2002) found that a lack of knowledge of recommended self-care behaviour had a detrimental effect on adherence. It seems, then, that knowledge about the illness, its treatment and recommended behaviours is fundamental in enabling individuals with heart failure to self-care effectively.

Comparatively little is known about psychological factors such as personality and self-care in heart failure. One study by Schiffer (2007), found that individuals with type-D personality, characterised by negative affectivity and social inhibition (Denollet and Brutsaert, 1998), experienced symptoms which were more often appraised as worrying than those with other personality traits. However, they were also less likely to report these symptoms.

A small number of studies have used the CSM to examine illness beliefs and predict self-care behaviour in heart failure. Voelmeck (2006) explored illness representations, self-care and HRQoL in a sample of 98 heart failure patients in the US. Using the IPQ-R, SCHFI and the Minnesota Living with Heart Failure Questionnaire (MLHFQ), no significant correlations were found between self-care scores and either illness representations or HRQoL. In a similar study, Morgan (2008) explored relationships between illness representations (IPQ-R), psychological well-being (Hospital Anxiety and Depression Scale, HADS), self-care (EHFScBS), and HRQoL (Kansas City Cardiomyopathy Questionnaire) in a sample of 161 heart failure patients in the Republic of Ireland. In contrast to the findings of Voelmeck (2006), illness representations explained a significant proportion of the variance in each of the study outcomes. More variance in self-care behaviour (8%) was explained by illness representations than illness-related or demographic factors. Albert and Zellar (2007) also found weak but statistically significant correlations between the accuracy of illness beliefs, as determined by the SIBHFT, and adherence ( $r = 0.12$ ,  $p \leq 0.05$ ) and self-care management ( $r = 0.12$ ,  $p \leq 0.05$ ). Fox et al (2001), using the IPQ-R, studied the congruence of illness representations between 60 older heart failure patients and their spouses and the relationship to adherence behaviour. Adherence was increased when patients and their spouses held congruent beliefs in relation to the illness representation of control.

In relation to treatment beliefs, only one study by Ekman et al (2006) was found that examined treatment beliefs and medication adherence in heart failure. Here, a strong belief that medication would improve symptoms was positively associated with medication adherence.

In summary, published studies suggest that socio-demographic factors, the healthcare system, the illness and its treatment and patient-related factors influence self-care in heart failure although this evidence is, at times, inconclusive. The relationship between illness and treatment beliefs and self-care, which is the focus of this research, has been considered in only a few of studies, again with conflicting findings.



## 2.5 CONCLUSION

In conclusion, four main areas of literature have been examined in this chapter: the nature and management of heart failure from a predominantly biomedical perspective, lay beliefs and social and psychological perspectives of health, illness and treatment, self-care policy and practice and finally, the factors influencing self-care in heart failure, including illness and treatment beliefs.

In summary, heart failure is a prevalent clinical condition with wide ranging implications for the individual, their family and wider society. Defining heart failure can be problematic not only because of the many different types of failure but also because of the lack of a definitive diagnosis at times. Health and social care financial costs are high and are set to increase in the future. Clinical management presents a number of challenges not least because the cause of heart failure may be difficult to determine in many individuals and co-morbidities are common. Management is predominantly through drug therapy but other treatments are becoming more widespread such as pacemaker devices. Prognosis is often difficult to predict which can mean that making the decision to move to a palliative care approach can be problematic.

The experience of living with heart failure, from a patients' perspective, is also challenging and can be viewed as a major disruption in an individual's life course. A large number of relatively non-specific symptoms may be experienced by individuals and it is suggested that differentiating symptoms from the effects of ageing and medication may be difficult. Furthermore, the presence of a high number of co-morbidities in this population may make the construction of a coherent picture of the illness and treatment more difficult.

Lay beliefs about illness have influenced the development of a number of models which attempt to explain and predict behaviour. The CSM (Leventhal et al, 1980) is widely used as a theoretical framework. Its main strengths are that it recognises an emotional influence on behaviour and views the interaction between beliefs and behaviour as a dynamic system involving a cognitive appraisal of outcomes which then feedback to influence beliefs. Illness representations, according to this model, have been measured extensively using the IPQ-R (Moss-Morris et al, 2002) and there is much support for its predictive ability of a number of health-related outcomes. It has been proposed by Horne (1997) that the CSM be extended to include treatment beliefs, involving beliefs about the necessity of and concerns about medication. The BMQ (Horne et al, 1999) which measures treatment beliefs has been useful in predicting adherence to medication in some illnesses.

Self-care, including medication adherence, has been established health and social care policy in the UK for the past decade. Applied to heart failure, self-care has been visualised as a decision-making process involving making choices related to lifestyle behaviour and taking medication (self-care maintenance) and recognising symptoms and taking actions (self-care management). In UK policy, the definition of self-care also includes those actions taken to maintain emotional and social well-being, not just adherence to recommended lifestyle behaviour and medication. The reported level of self-care in heart failure varies widely and seems to be dependent on both context and methodology. In measuring self-care in heart failure, although other measures exist such as the SCHFI (Riegel et al, 2004), the EHFS CBS (Jaarsma et al, 2003) has been used in a number of European studies and has been found to have an acceptable level of reliability in a UK population. However, there is an emphasis on adherence behaviours with more limited inclusion of self-management strategies or emotional and social activities. This may be because the development of this scale was led by expert nurses according to a biomedical model of illness rather than viewed from a patient perspective.

Factors affecting self-care in heart failure have been extensively studied especially in relation to adherence behaviour. These factors can be categorised as socio-economic, healthcare, condition, treatment and patient-related. Of these, there is most evidence for the influence of social support, patient-provider relationships, the presence of co-morbidities, the complexity of the drug regimes and the presence of cognitive impairment on self-care. However, there is more conflicting evidence in relation to age and gender, severity of illness and functional ability on self-care. Limited evidence exists for the influence of illness and treatment beliefs. Where evidence does exist, it is, again, conflicting. Voelmeck (2006) found no correlations between illness representations and self-care which is in contrast to the findings of Morgan (2008) and Albert and Zellar (2007), although only weak correlations were found in this earlier study. Only Ekman et al (2006) suggest a possible association between beliefs about the necessity of heart failure medication and adherence.

Arguably, a need exists to develop an understanding of illness and treatment beliefs in a UK, heart failure population and to determine any relationship between these beliefs and self-care behaviour. This understanding may mean that targeted interventions aimed at changing beliefs and enhancing self-care could then be developed.

The CSM has proved to be a useful framework for exploring beliefs and their relationship to health outcomes in other illness populations. The measurement of illness

representations through the IPQ-R, and treatment beliefs through the BMQ, are generic questionnaires and so should first be adapted for use in heart failure. The use of the EHFS CBS in measuring self-care, though illness-specific, needs to be scrutinised for its applicability to a UK, heart failure population.

From this review, qualitative and quantitative studies have enhanced the understanding of the experience of living with heart failure and the relationship between beliefs and self-care. Combining qualitative and quantitative approaches in a single study would enable both an exploration of the topic and allow relationships between illness representations, treatment beliefs and self-care to be determined. The following chapter discusses the methodology and methods used in this study.

### **CHAPTER THREE: METHODOLOGY AND OVERVIEW OF METHODS**

This purpose of this chapter is to present the research design, analyse the methodology and present an overview of the methods employed in this study. First, a reminder is given of the aims and objectives of the research before summarising the overall design. The philosophical basis of the dominant paradigms in health and social care research is discussed before defining mixed methods and briefly tracing the historical and philosophical development of this methodology. A typology of mixed methods is presented and the model used in this research is identified and discussed. For clarity, although an overview of the methods is given here, detailed discussion of the methods and procedures is given in Chapters four, five and six in relation to each phase of the study. Discussing the methods and results of each phase in sequence is a structure common in the write-up of mixed methods research (Creswell and Plano Clark, 2007). However, to avoid repetition, aspects of method which are common to both phases of the study, namely, the research setting, permissions and access to participants are discussed here.

As stated in the introduction, the aims of the research were to explore illness representations, treatment beliefs and self-care in heart failure and to determine relationships between these variables. The objectives were to conduct semi-structured interviews with a sample of heart failure patients to explore illness representations, treatment beliefs and self-care; to adapt or develop as necessary, questionnaires measuring illness representations, treatment beliefs, socio-demographic factors and self-care and to use these questionnaires to determine relationships between these variables in a cross-sectional survey.

A mixed methods research design was chosen, using an exploratory, instrument development model as defined by Creswell and Plano Clark (2007). The research was conducted in two sequential phases: Phase one explored illness representations, treatment beliefs and self-care in a sample of people with heart failure using qualitative methods. The findings from this phase were used to adapt and develop three questionnaires measuring illness representations, treatment beliefs and self-care. A socio-demographic questionnaire was also developed. Following a pilot study, in phase two, illness representations, treatment beliefs and self-care were examined in a cross-sectional survey and relationships between these variables were determined using quantitative methods.

This design was chosen as it was thought necessary to first explore the phenomenon of beliefs and behaviour in this population from a patient perspective, best achieved using qualitative methods. Findings could be used to inform the development of measurement instruments, specific to heart failure. Relationships between beliefs and behaviour could then be tested in a larger sample, best achieved using quantitative methods. By integrating qualitative and quantitative findings in this way, it was anticipated that a more complete understanding of the topic could be achieved.

### **3.1 THE DOMINANT PARADIGMS IN HEALTH AND SOCIAL CARE RESEARCH**

In order to locate this research within a philosophical paradigm, this section begins with a discussion of what is meant by the term 'paradigm' and the different ways in which researchers have defined this. The development of the view that alternative paradigms are incompatible will be traced. The positivist or postpositivist and constructivist or interpretivist philosophical views will be compared and contrasted and the development of paradigms will be considered before discussing the view that we are now entering a third methodological movement – that of mixed methods research (Tashakorri and Teddlie, 1998).

#### **3.1.1 Defining paradigms and the incompatibility thesis**

The use of paradigms as a way of describing researchers' beliefs about their work can be traced from Kuhn (1970) in 'The structure of scientific revolutions'. Kuhn defined paradigms in a number of ways. A broad definition is that of a 'worldview' or an all-encompassing way of viewing and experiencing the world. In research terms, the most popular definition of a paradigm is '*A basic set of beliefs that guide action*' (Guba and Lincoln, 1995, p.105). Both these broad definitions emphasise what Morgan (2007) describes as the 'metaphysical' basis of research, that is, abstract ideas about truth, reality and moral values. An acceptance of these broad definitions suggests that individual researchers hold a system of beliefs about the world which are so fundamental and integral to their thinking that it would be impossible to work within an alternative paradigm.

According to Morgan (2007) it was this emphasis on metaphysical concerns that served to differentiate qualitative from quantitative research, leading to the belief that alternative paradigms and crucially, the research methods that they traditionally employ, are incompatible. That is, it is impossible to hold opposing paradigmatic views. Howe (1988) coined this 'the incompatibility thesis'. Advocates of these opposing paradigms, according to Gage (1989), have focused on debating the superiority of either a quantitative or a qualitative approach. As a result, researchers have been limited to single-method studies

in the belief that quantitative and qualitative techniques are incompatible due to fundamental and diametrically opposed differences in their philosophy (Tashakkori and Teddlie, 1998).

Challenging this view, Morgan (2007), argued how Kuhn himself identified at least two other, more specific, definitions of the term paradigm. Paradigms can also be viewed as shared beliefs among members of a research community which determines what questions should be answered and the methods best employed in answering them. Alternatively, a paradigm can also be defined as an example or model of how research is carried out in a specific field. If these definitions of a paradigm are applied, it is suggested that researchers have the freedom to work with a number of different research methods, opening up the possibility of mixed methods research.

### **3.1.2 Comparison of the dimensions of the dominant research paradigms**

Guba and Lincoln (1995) discussed the nature of the dominant paradigms in terms of ontology, epistemology, axiology and methodology. These authors define ontology as the study of the nature of reality, its form and what can be known about it. Epistemology is concerned with the nature of the relationship between the researcher and what can be known, and the nature of truth. According to Guba and Lincoln (1995), epistemology, therefore, is inexorably linked to ontology. For example, if one assumes that there is a single, external reality then the researcher remains detached and objective in order to discover that reality. Axiology is concerned with moral values and the importance of value-free research. Again, this is linked to epistemology in practical terms, in that a researcher adopting a subjectivist stance would also presumably support a value-laden axiology.

Finally, and arguably most significant, is the issue of methodology. This concerns the reasoning or logic of the research. Deductive reasoning is theory-driven and involves the testing of *a priori* hypotheses. Inductive reasoning begins with observation with a view to recognising patterns and developing theory. Methodology also includes the nature of the findings in terms of the extent to which they are context-dependent or generalisable and the justification for the research design and processes (methods). Ideas about ontology, epistemology and axiology are often seen as fundamental to the research process, underpinning methodological issues and, hence, determining the choice of methods (Crotty, 1998).

The dominant paradigms of positivism/postpositivism and interpretivism/constructivism are discussed before identifying an alternative philosophical position. Positivism was developed by the logical positivists and later developed by Karl Popper to be called

postpositivism. According to Guba and Lincoln (1995) a postpositivistic stance emphasises a critical realism in that there is single, external reality but this can only be understood imperfectly. The researcher takes an objectivist stance and assumes findings are probably true but subject to falsification. This follows the assertion by Popper that knowledge develops not through proving an hypothesis, which is impossible, but by disproving or falsifying theory and presenting an alternative hypothesis. For Popper, the belief that a hypothesis is always subject to falsification defines the scientific method (Magee, 1985). Researchers strive for value-free inferences and the emphasis is on deductive logic and testing theory. The research design is largely experimental or quasi-experimental using quantitative methods.

Seemingly diametrically opposed to the positivist/postpositivist position is the constructivist or interpretivist viewpoint (originally called naturalism) by Guba and Lincoln (1995). The ontological basis is described as relativist in that realities are believed to be multiple and constructed by the individual. They are not held to be 'true' in any absolute sense. The researcher and the researched are inexorably linked so that the research is laden with the values and the subjective experience of the researcher. There is an emphasis on inductive reasoning and qualitative methods with the recognition that inferences are dependent on the context in which the research takes place. These philosophical positions are frequently presented as representing opposing points of view in terms of each paradigmatic dimension.

These dominant paradigms are compared and summarised according to ontology, epistemology, axiology and methodology in Table 3.1, adapted from Creswell and Plano Clark (2007, p.24) and Guba and Lincoln (1995, p.164). For comparison, the dimensions of a pragmatic paradigm are included as this has been selected as the philosophical basis of this research (discussed in section 3.2.2).

**Table 3.1:** Summary of the Paradigmatic Dimensions of Positivist/Postpositivist, Constructivist/Interpretivist and Pragmatic Research

<b>Dimension</b>	<b>Positivism/ Postpositivism</b>	<b>Constructivism/ Interpretivism</b>	<b>Pragmatism</b> (section 3.2.2)
<b>Ontology</b> The nature of reality	A single reality	Multiple realities – reality is socially constructed	Singular and multiple realities
<b>Epistemology</b> The relationship between the researcher/ researched; The nature of truth	Objective  A single, absolute truth	Subjective  Multiple truths	Objective and subjective  Singular and multiple truths
<b>Axiology</b> Moral values	Value-free (unbiased)	Value-laden (biased)	Value-free and value-laden
<b>Methodology</b> Reasoning; Inferences	Deductive reasoning; Inferences are generalisable	Inductive reasoning; Inferences are context dependent	Abductive reasoning; The degree of transferability

### **3.1.3 Tracing the development of quantitative, qualitative and mixed methods**

Kuhn's (1970) description of how paradigms develop enables an exploration of the shift from a positivist/postpositivist paradigm employing largely quantitative methods, to a constructivist or interpretivist paradigm using qualitative methods and, arguably, to a mixed methods approach in health and social science research. Kuhn (1970) describes how a new idea is initially resisted as it threatens the established order. This idea is then gradually accepted until it too becomes institutionalised. A new, revolutionary idea then emerges. In nursing, research has been based on 'borrowing' traditions from other disciplines, most notably medicine. Early nursing research was therefore, drawn from a positivist paradigm with research primarily focused on outcome measures using predominantly quantitative measures (Twinn, 2003).

Since the 1980s, qualitative research has been in ascendance, establishing at least equal dominance in health research. Within nursing, the recognition that the complexity of health and illness and the nature of the human experience could not adequately be understood in purely scientific terms, led to a growing acceptance of qualitative research as a way of understanding health and nursing practice in terms of its social, behavioural, psychological, political, cultural and environmental influences (Twinn, 2003). In the social sciences, the paradigmatic shift was led by qualitative researchers, most notably, Lincoln and Guba (1985) who argued that the claims made by positivists and postpositivists were unrealistic and the alternative view of constructivism enabled a better understanding of the social world.



Tashakkori and Teddlie (2003) argue that we are currently experiencing a third paradigm shift to mixed methods research. Morgan (2007) also describes a move away from the metaphysical paradigms as there is an unclear relationship between metaphysical beliefs and the practical application of research methods. Guba and Lincoln (1995) agree that it is unlikely that the discussion of metaphysical dimensions closely describes what the researcher thinks or does and that *'workaday scientists rarely have either the time or inclination to assess what they do in philosophical terms'* (Guba and Lincoln, 1995, p.117).

Mixed methods research is described by leading authors as in an adolescent stage with many unresolved issues, not least, its philosophical basis. The degree of acceptance of mixed methods as the dominant research paradigm, as envisaged by Tashakkori and Teddlie (1998) and Morgan (2007), remains to be seen. However, currently, interest in mixed methods research is evidenced by the proliferation of published research articles. Plano Clark (2005) found more than 60 published articles in health and social science journals employing mixed methods in 2004. The Journal of Mixed Methods Research was launched in 2005, the year which also saw the first international, multidisciplinary conference on mixed methods. A review of research commissioned by the Health Research and Development Programme in the UK found that 30% were mixed methods between 2000 and 2004 compared to 17% before this period (O'Caithain et al, 2007).

### **3.2 IDENTIFYING MIXED METHODS AS THE RESEARCH DESIGN**

The section begins by defining mixed methods and presents a rationale for the selection of this design in this study. The historical and philosophical development of mixed methods will be briefly traced before analysing the different types or models of mixed methods. Finally, the rationale for the use of the specific model used in this research will be discussed.

#### **3.2.1 Defining mixed methods and the rationale for its use in this study**

Creswell and Plano Clark (2007, p.5) define mixed methods as:

*'A research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis of data and the mixture of qualitative and quantitative approaches in many phases of the research process. As a method, it focuses on collecting, analysing and mixing both quantitative and qualitative data in a single study or series of studies. Its central premise is that the use of quantitative and*

*qualitative approaches, in combination, provides a better understanding of research problems than either approach alone'.*

This definition, although lengthy, has been selected as an operational definition as it brings together three main elements common in other definitions, for example, those of Greene and Caracelli (1997) and Tashakkori and Teddlie (1998; 2003). Namely, that mixed methods is a methodology not just a method, that it combines qualitative and quantitative methods in the same study and that this combination 'adds value' to the research. A further advantage of mixed methods is that the strengths of one method may offset the limitations of the other. This is frequently referred to as 'methodological triangulation' and is the historical basis of mixed methods research (Jick, 1979). The main strengths and limitations of quantitative and qualitative methods are outlined below.

Quantitative methods commonly involve large, representative samples so there is often a high degree to which findings can be generalised. In this way the research question is addressed in a broad, general sense not just in isolated circumstances (Miles and Huberman, 1994). It allows for greater objectivity as there is an effort to avoid personal bias so that researchers aim to keep a 'distance' from participants. Procedures are employed to maximise validity and reliability and described in detail so that the research may be replicated. Importantly, quantitative methods facilitate comparisons across categories and over time. In this way, the relationship between categories can be established (Kruger, 2003). However, this also means that quantitative methods often collect a much narrower and arguably, more superficial range of data. Results are limited to numerical descriptions rather than detailed narrative. The development of standard questions by researchers can lead to 'structural' bias, where the data actually reflected the view of the researcher instead of the participant. To some extent this can be overcome by deriving assumptions about which constructs are worth measuring, on qualitative data (De Vaus, 1996).

In comparison, qualitative data provides depth and detail and can generate new theories or allow the description of existing phenomena and current situations. In doing so, it can facilitate a more complete understanding of the human experience (Denzin and Lincoln, 2005). The collection and analysis of qualitative data is highly dependent upon the researcher's personal attributes and skills. This subjectivity, including personal experience and insight, is often described as a strength of qualitative data but also makes objectivity impossible so that results are less easily generalised and it may be difficult to make

systematic comparisons. Furthermore, it may be difficult to replicate a piece of qualitative research as data collection is highly context dependent.

In this study, the main anticipated value of mixed methods is in providing a more complete understanding of the research problem. An understanding of the relationship between illness representations, treatment beliefs and self-care in heart failure requires the use of objective quantitative methods to determine those relationships and examine the extent to which findings can be generalised to the population of heart failure patients as a whole. The development of valid and reliable measures of these variables is best derived from the experience of people with heart failure in their own words, which is best determined by qualitative means. The interpretation of the quantitative data will also be enhanced by the rich description of the qualitative data so that the context within which results occur can be described.

### **3.2.2 The historical and philosophical development of mixed methods – the introduction of pragmatism**

The history of mixed methods can be traced from Campbell and Fiske (1959) who used multiple forms of quantitative data in a study of psychological traits. They used the term 'multi-method' to describe this. The purpose of using more than one method was to ensure that it was the phenomenon in question that was being studied rather than the method used to study it. The term multi-method research has since been frequently used interchangeably with the term mixed methods. To differentiate these terms, Tashakkori and Teddlie (2003) defined multi-method research as the use of multiple qualitative *or* quantitative methods, for example, the use of a survey and experiment in a quantitative study or participant observation and a case study in a qualitative study. Jick (1979) discussed the triangulation of qualitative and quantitative data, the purpose of which was to offset the weaknesses of one method by the strengths of the other. Mixed methods research is, therefore, commonly described as evolving from multi-method research and triangulation which still represents one type of mixed methods design. Creswell and Plano Clark (2007) have called the emergence of multi-method and triangulation designs as the 'formative period' in mixed methods research.

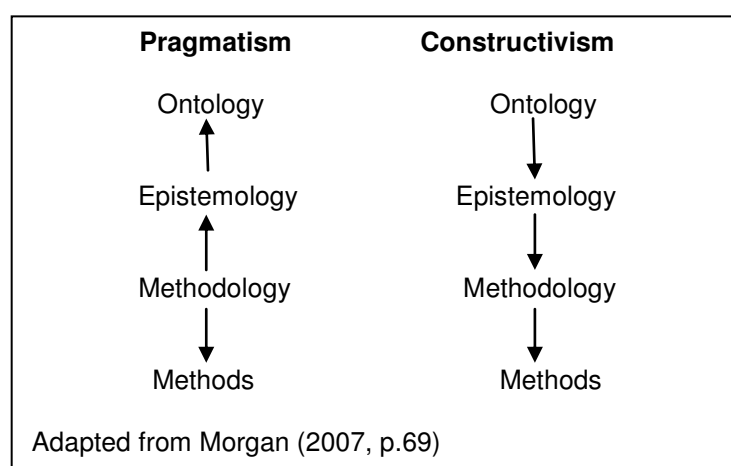
The 1970s and early 1980s has been called the 'paradigm debate period' by Tashakkori and Teddlie (2003), during which discussion took place on the philosophical basis of mixed methods. The debate focused on whether it was acceptable to use a number of paradigms or accept an alternative paradigm, most commonly the philosophy of pragmatism. Despite the assertion by Tashakkori and Teddlie (2003) that mixed methods

has moved on from this debate, determining the philosophical basis of this research design is ongoing. Greene and Caracelli (1997) argued that mixed methods can use different paradigms as long as it is explicit when each is used. This stance does not seek to reconcile alternative paradigms and accepts the incompatibility thesis, acknowledging the tensions and oppositions. Creswell and Plano Clark (2007) believe the choice of paradigm is dependent on the type or model of mixed methods design. Alternatively, many mixed method researchers, including Tashakkori and Teddlie (2003), call for 'pragmatism' as the philosophical foundation for mixed methods research, arguing that the research question should be of primary importance rather than either the methods or philosophical paradigm.

Pragmatism was first developed by the American philosopher and scientist Charles Peirce (1839-1914). Its meaning is derived from the Greek word '*pragma*', meaning action. It emphasises the practical relationship between humans and the world. In a discussion of pragmatism by Delanty and Strydom (2003), Cartesian dualisms such as subject and object, deduction and induction are rejected. Knowledge is grounded in real collective problems and the development of knowledge occurs in different ways and in a variety of contexts. The meaning of a concept can be understood by engaging in a 'practical consideration', which takes account of the effects or practical consequences that might result from it. For Pierce, knowledge develops through 'abduction' (inductive and deductive reasoning) which involves both feeling or intuition and experience or direct observation. The development of knowledge involves co-operative interpretation, discussion and argument within scientific communities.

Dewey and Mead in the 1920s and 1930s, applied pragmatism to social science, rejecting the separation between theory and practice and claimed that in social inquiry, practice is intrinsic not extrinsic and determined by an 'end-in-view' or the potential consequences of the inquiry. Maxcy (2003) described pragmatic research as that in which the methods are determined according to '*what works*'. Rorty (1979) used the term 'transcendental pragmatism' and called for the abandonment of the attempt to lift ourselves, in cognitive terms, to a position outside the world in order to view things from a purely ontological standpoint which separates us from the practical engagement with the world on which knowledge is based. For pragmatists, epistemological considerations are not ignored; rather the methodology is the prime consideration and connects the epistemology on the one hand and practical methods on the other (Figure 3.1). The top-down privilege of ontology in the constructivist/interpretivist paradigm is rejected.

**Figure 3.1** Relationships between Metaphysical and Methodological Considerations in Pragmatic and Constructivist/Interpretivist Research



Howe (1988) describes pragmatic philosophy as deconstructive in that it attempts to examine concepts such as ‘truth’ and ‘reality’ but prevents them from being turned into ‘super-concepts’ and, thereby, generating problems that cannot be solved. In rejecting dualisms, complete objectivity or complete subjectivity is unrealistic. Pragmatic researchers move between these extremes in an intersubjective way. Similarly, there is both a ‘real’ world and a subjective reality. The issue of transferability rejects the notion of context-dependent or generalisable inferences. The important issue is the extent to which findings can be transferred and the factors which influence this (Morgan, 2007). Tashakkori and Teddlie (2003) go as far as to suggest that the dichotomy between positivism/postpositivism and constructivism/interpretivism should be abandoned along with the metaphysical constructs of truth and reality. Rather, pragmatism as a practical and applied research philosophy should guide methodological choices. Twinn (2003) acknowledges this but argues that there has been little debate about the use of alternative philosophies, such as pragmatism, within nursing research.

In this research, the philosophy of pragmatism is applied in terms of methodology, epistemology, ontology and axiology. Reasoning is both inductive and deductive in phase one (using qualitative methods) and deductive in phase two (using quantitative methods). The relationship between the researcher and the participant is largely subjective in phase one with attempts made to maximise objectivity in phase two, as such there is assumed to be both a ‘real’ world and a subjective reality. The influence of the values of the researcher is recognised in phase one, with attempts made to minimise researcher bias in phase two.

It could be argued that the use of qualitative methods in order to develop quantitative survey instruments sits within a postpositivist paradigm in that the ultimate aim of determining relationships between illness representations, treatment beliefs and self-care, assumes an external reality and emphasises the objective role of the researcher. Giddings and Grant (2007) might agree, when they describe the use of mixed methods in this way as 'a Trojan horse for positivism'. However, the qualitative findings in this research are not only used to develop the questionnaires but also to illuminate the quantitative findings so that inferences are not made on the quantitative data alone. In this way, no data set has assumed preference over the other.

Whilst the philosophical debate is still evident, it is argued that mixed methods has moved on to a third period in its history – namely the discussion of its methods and procedures (Tashakkori and Teddlie, 1998).

### **3.2.3 A typology of mixed methods**

Many typologies or classifications of mixed method research designs have been proposed. A seminal article by Greene et al (1989) described the first comprehensive classification system of mixed method designs. Since then, more than twelve classification systems have been developed by authors in a number of disciplines including nursing (Sandelowski 2000; Morse, 1991), health (Morgan 1998; Steckler et al 1992), social policy (Patton, 1990), education (Creswell and Plano Clark, 2007; Creswell et al 2003; Creswell, 1999) and educational psychology (Tashakkori and Teddlie, 2003; 1993).

Morse (1991) introduced a notational system, using the abbreviations 'Qual' for qualitative and 'Quan' for quantitative. Two types of mixed method design were identified - simultaneous and sequential triangulation. A simultaneous design is one in which qualitative and quantitative data are collected and analysed concurrently. In a sequential design, data are collected and analysed separately and in sequence. The symbol '+' was used to denote a simultaneous design and '→' to denote a sequential design. Morse (1991) also introduced the concept of dominance in mixed methods research. Upper case letters were used to denote a dominant phase with lower case letters representing a less dominant phase. For example, QUAN + qual, describes a simultaneous design in which the quantitative data are given priority. QUAL → quan, describes a sequential design in which qualitative data are dominant and collected first.

In reviewing the typologies, Creswell and Plano Clark (2007) highlighted a number of difficulties. Firstly, the terminology was often discipline specific and used inconsistently. For example, Bryman (2007) argues that the term triangulation is now relatively

meaningless due to the many ways in which it has been defined in published work and has called for its use to be temporarily abandoned. Different terms have also been used to mean the same thing, for example, simultaneous (Morse, 1991) and concurrent (Creswell et al, 2003). Furthermore, the issue of dominance is now challenged with some authors questioning whether it is necessary to establish the relationship between dominant and less-dominant phases (Tashakkori and Teddlie, 2003). Typologies are also based on different criteria such as procedures (Tashakkori and Teddlie 1998) or purpose (Greene et al, 1989).

The typology according to Creswell and Plano Clark (2007) has been selected as the methodological framework for this research and is outlined below. The rationale for this choice is that firstly, it represents the current thinking in mixed methods research and secondly, the typology is designed to be functionally useful to researchers undertaking mixed methods research which seems congruent with a pragmatic, philosophical position of 'what works'. Finally, the classification of an 'exploratory design, instrument development model' accurately describes the research design applied here. The typology consists of four major designs – triangulation, embedded, explanatory and exploratory. Within these overall designs are a number of specific models (Table 3.2).

Three key decisions are described in determining the specific design and model. These decisions involve timing, weighting and mixing. Timing refers to the sequencing of the study and the relationship between the quantitative and qualitative components. Timing can be concurrent or sequential. Concurrent timing occurs when the qualitative and qualitative data are collected in a single phase of the study. In sequential timing, data are collected in two distinct phases – collecting and analyzing one type of data before using the other. Either data type can be collected first. Weighting refers to the relative emphasis or priority of the approaches. Quantitative or qualitative data may be given priority or equal dominance is assumed. Morgan (1998) argues that weighting should be determined by the relative strength of the data set which is best suited to address the purpose and aim(s) of the study. Mixing is the explicit relationship between the two data sets. Three types of mixing exist; merging the data set during analysis, embedding one data set within a larger data set or connecting the data sets where the analysis of one type of data leads to the collection of the second type of data.

**Table 3.2**      **Summary of a Mixed Method Typology**

<b>Design Type</b>	<b>Model</b>	<b>Timing</b>	<b>Weighting</b>	<b>Mixing</b>	<b>Notation</b>
<b>Triangulation</b>	Convergence; Data transformation; Validating quantitative data; Multilevel	Concurrent: quan/qual at the same time	Usually equal	Data merged during analysis	QUAN + QUAL
<b>Embedded</b>	Embedded experimental; Embedded correlational;	Concurrent or sequential	Unequal	Embed one data type within a larger design using the other data type	QUAN (qual) or QUAL (quan)
<b>Explanatory</b>	Follow-up explanations; Participant selection;	Sequential: quan followed by qual	Usually quan	Connect the data between the 2 phases	QUAN → qual
<b>Exploratory</b>	Instrument development; Taxonomy development	Sequential: usually qual followed by quant	Usually qual	Connect the data between the 2 phases	QUAL → quan or qual → QUAN or equal

Creswell and Plano Clark (2007, p.85)

### **3.2.4 The research design**

This study uses an exploratory design, instrument development model to explore illness representations, treatment beliefs and self-care in heart failure and to determine relationships between these variables according to the aims of the research.

According to the typology (Creswell and Plano Clark, 2007), an exploratory design is conducted in two sequential phases where the results of the first, qualitative method develop or inform the second, quantitative method. The central premise is that an initial exploration of the topic is necessary. In the instrument development model, the topic is first explored with a small number of participants. These qualitative findings are then used to guide the adaptation or development of instruments to be used in a quantitative survey. In the second phase, these instruments are validated and implemented. The two phases are therefore, connected by the adaptation or development of the instruments.

Here, the aim was to explore illness representations, treatment beliefs and self-care in a small sample of heart failure patients using qualitative methods. These results were then used to adapt or develop as necessary, existing questionnaires measuring illness representations (the IPQ-R, Moss-Morris et al, 2002), treatment beliefs (the BMQ, Horne

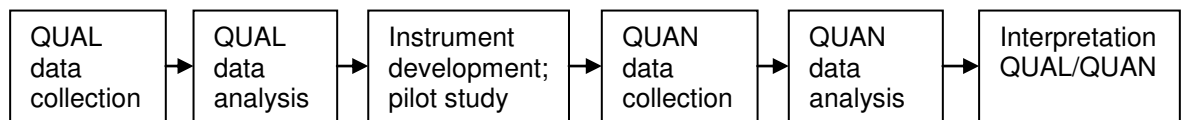


et al, 1999) and self-care in heart failure (the EHFScBS, Jaarsma et al, 2003). These questionnaires were then used in a cross-sectional survey to determine relationships between these variables according to the second aim of the study.

This design was selected as it is proposed that there are some limitations in existing instruments used to measure illness representations, treatment beliefs and self-care in heart failure. Whilst the IPQ-R and BMQ are considered reliable and valid, their use in a UK population of heart failure patients is unknown. The authors themselves assert that these instruments need to be adapted for use in specific illness populations (Moss-Morris et al, 2002; Horne et al, 1999). The EHFScBS has been shown to be valid and reliable in a Swedish population although it has been suggested that it may be less reliable in a UK population (Shuldham et al, 2007). Hence, it is argued that there is a need to first explore these variables qualitatively in order to adapt these instruments for use in this study population.

Equal dominance is assumed between the qualitative and quantitative phases. Data are primarily connected through the adaptation of the questionnaires from the qualitative data. However, both qualitative and quantitative findings are both considered in an overall discussion of the results. Hence, this study is identified by the notation QUAL→QUAN. Figure 3.2 details this research design.

Figure 3.2      An Exploratory, Instrument Development Model



A strength of this model, according to Creswell and Plano Clarke (2007), is that since the phases are predominantly separate, the design is relatively straightforward. However, it is also time-consuming and it may be difficult to gain ethical permission for the study since the second phase cannot be described in detail at the outset. Furthermore, it may be difficult to decide which qualitative data to use in order to adapt or build the instruments (Creswell and Plano Clark, 2007). These issues are discussed further in Chapters four, five and six.

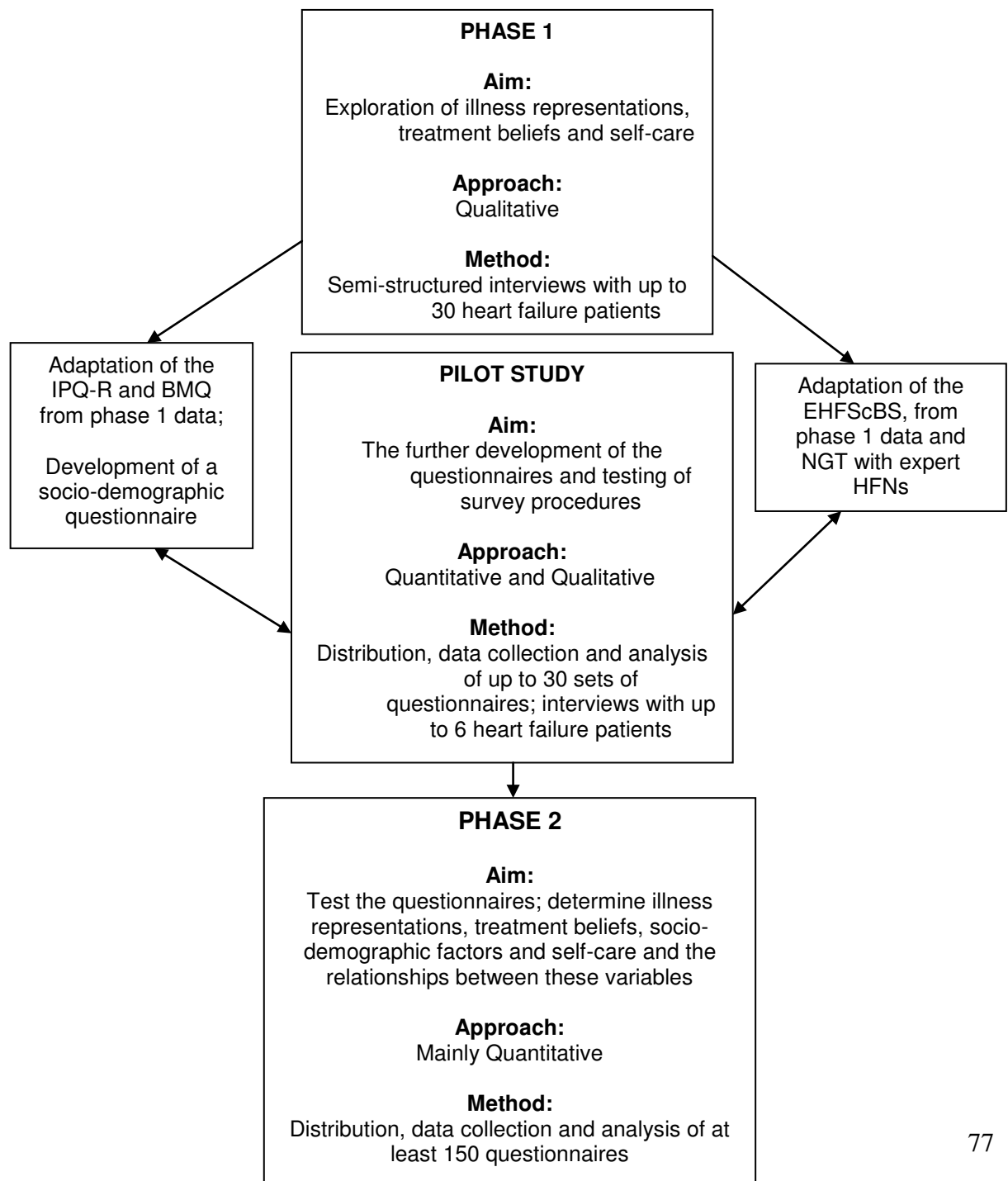
### 3.3 OVERVIEW OF METHODS AND GENERAL CONSIDERATIONS

In this section, an overview of the methods employed is given followed by a discussion of aspects of method common to both phases of the research, namely, the research setting, access to participants and permissions.

#### 3.3.1 Overview of methods

An overview of the methods and procedures in relation to the aims of the research is given in Figure 3.3.

Figure 3.3. Overview of Methods and Procedures



As indicated in section 3.2.4, the research was conducted in two sequential phases. Phase one was the collection and analysis of qualitative data with a small sample of participants with heart failure, using semi-structured interviews. These data were then used to adapt three questionnaires, the IPQ-R, BMQ and the EHFScBS. The views of an expert group of heart failure nurses (HFNs) were also sought in the adaptation of the self-care questionnaire using a nominal group technique (NGT). A questionnaire assessing socio-demographic characteristics was developed in order to accurately describe the sample. In the pilot study, the process of data collection and methods of data analysis to be used in the main survey were tested. The questionnaires were then further amended based on the pilot study and following discussion with a small number of heart failure patients (member checks). In phase two, quantitative data were collected in a larger sample of heart failure patients. The final questionnaires were tested for reliability and validity and data were analysed to determine illness representations, treatment beliefs and self-care in this sample and the relationships between these variables. Consideration was also given to the influence of socio-demographic factors on self-care.

### **3.3.2 The research setting**

The research took place in three NHS Primary Care Trusts (PCTs) in one County of South East England. These PCTs were nearest, geographically to the researcher and so were chosen for convenience. For the purpose of this research, these PCTs have been labelled Sites A, B and C. Site A is the largest, serving a population of 710,000 people. Site B serves 655,700 people and Site C, the smallest, serves a population of 270,000 people (KCC website, 2010).

Multiple sites were chosen in order to draw from a wider and potentially more diverse population and to offer a large sample size. This was important in terms of the generalisability of findings and statistical significance of the results. Accessing a number of sites also served to spread the workload of the HFNs whose support was necessary, not only to recruit participants, but also to develop the self-care questionnaire.

A community or primary care setting was chosen rather than secondary or tertiary care, for a number of reasons. Firstly, it was felt that this was the most appropriate setting in which to study self-care which addresses the day-to-day actions of people who are living with illness who are supported, but not directly supervised by, healthcare professionals. A community setting also offered the opportunity for a much larger sample size compared to secondary care. It was also felt that ethically, there was reduced potential for harm in selecting community-based patients as it was necessary to question them about some

potentially distressing aspects of their illness. Answering such questions whilst experiencing an acute exacerbation of symptoms may have caused additional distress for patients who might be physically and emotionally vulnerable when hospitalised.

### **3.3.3 Permissions and access to participants**

The research was undertaken according to research governance procedures set out by Canterbury Christ Church University (CCCU) as the sponsors of the research. Procedures set out by the Research Governance Framework for Health and Social Care (DH, 2005d) were also followed. Research Governance identifies a number of key standards in relation to the ethical involvement of research participants, the scientific quality of the research, information in terms of dissemination of findings and public access, health and safety of the participant and researcher, legal issues, financial regulation and the prevention of misconduct (CCCU, 2006).

Initially, the University Research Degrees Sub-Committee approved an outline proposal. A satisfactory peer review was obtained following some clarification of the procedures and broadening of the literature review. The procedure for ethical review was carried out according to CCCU regulations. Ethical permission was gained from the National Research Ethics Service (NRES) local committee following some clarification of procedures (Appendix 4). Creswell and Plano Clark (2007) recognise that gaining approval for phase two of an exploratory, instrument development model can be problematic as the data collection instruments are not available at the start of the study. In this case, a further approval by the NREC was required once the final versions of the questionnaires were developed (Appendix 5). The ethical principles which applied in this research are discussed in relation to each phase of the study in Chapters four, five and six. Permission for the research to take place within the PCTs was gained from the Research Management and Governance Centre for the locality (Appendix 6) following a required Criminal Records Bureau and occupational health check.

In order to gain access to participants, the lead HFN in each of the three PCTs was initially approached by telephone. These nurses were seen as the gatekeepers to the heart failure patients and so their co-operation was crucial in terms of recruitment. Agreement in principle was sought to allow access to the heart failure patients registered to their service and for their assistance in recruitment. The researcher was known personally to two of these nurses either through involvement in earlier research or in a professional capacity. On reflection, this existing relationship of rapport and mutual trust

was instrumental in ensuring the early and ongoing support of the HFNs and the success of the study.

Contributing to the relative ease of access was that the lead HFNs recognised a reciprocal benefit in supporting the research. The lead HFN in Site C saw supporting the research as an opportunity to educate her team in research methods, while at Site A, participating in the research allowed the team to achieve a strategic management target. The lead HFNs also supported the purpose of the study and saw the development of the self-care questionnaire, in particular, as potentially beneficial to their service. Beyond the initial access, the maintenance of the relationship between the researcher and the HFNs was dependent on regular contact through meetings, telephone calls and e-mails. Any changes to the procedures were first agreed with the HFNs. In conclusion, although gaining permissions for the research and allowing access to participants was a lengthy process, no significant difficulties were encountered.

In conclusion, this chapter has identified mixed methods as the research design, located within the philosophical paradigm of pragmatism. Specifically, an exploratory, instrument development model has been selected where illness representations, treatment beliefs and self-care in heart failure are first explored qualitatively before the adaptation of the questionnaires. These questionnaires are used to determine the influence of beliefs on self-care, in a cross-sectional, quantitative survey. As such, the collection of qualitative and quantitative data is sequential. Co-dominance is assumed with both data sets integrated in an overall discussion of the results.

An overview of methods and procedures has been presented and aspects of method common to both phases of the study have been discussed, namely, the research setting and permissions and access to participants. Detailed methods and procedures for each phase of the study in terms of sampling, recruitment and data collection and analysis methods are discussed in Chapters four, five and six.

## CHAPTER FOUR: THE QUALITATIVE PHASE – METHODS AND RESULTS

This chapter presents the methods and results of phase one, the collection and analysis of the qualitative data. The purpose of this phase was to explore illness representations, treatment beliefs and self-care in a sample of patients with heart failure in order to use these findings to inform the adaptation of the questionnaires used in the quantitative survey (phase two). Since relationships between these variables are measured quantitatively in phase two, the presentation of the qualitative data is primarily a discussion of the findings in relation to the literature and the theoretical framework. A secondary purpose was therefore, to test the applicability or ‘fit’ of the data to the CSM.

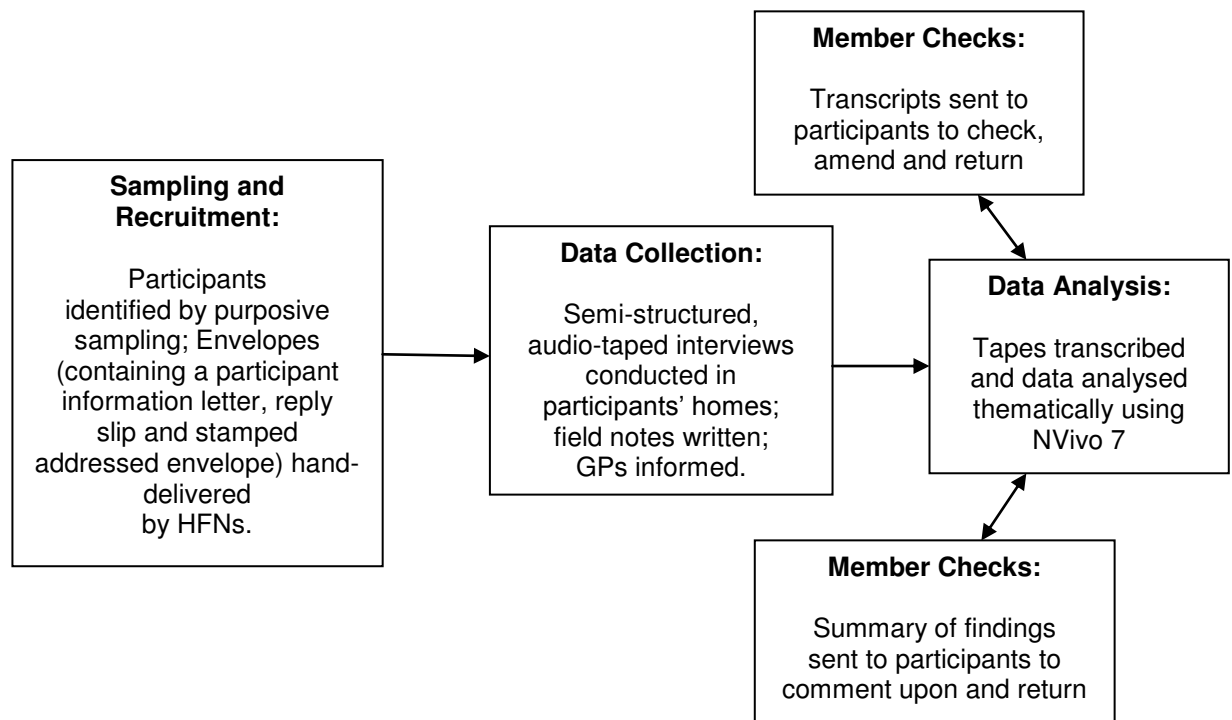
A summary of the procedures is given, followed by a discussion of the sampling strategy, recruitment of participants, data collection and analysis methods. Ethical considerations and the extent to which the data can be considered trustworthy is also discussed. In presenting the results, the characteristics of the sample are described before a discussion of the main findings.

### 4.1 METHODS

#### 4.1.1 Procedures

A summary of the procedures is given in Figure 4.1.

Figure 4.1      Summary of the Qualitative Procedures



The heart failure nurses (HFNs) selected 30 patients according to a purposive sampling strategy. Envelopes containing a participant information letter, reply slip and stamped addressed envelope were hand-delivered to patients by the HFNs. The patients were instructed to complete and return the reply slip with their name, address and contact details, if they were willing to take part. They were then telephoned to set up a mutually convenient date and time when the data could be collected.

Data were collected by semi-structured, audio-taped interviews in the participants' homes. On arrival, following introductions, the purpose of the study was explained and the participant information letter was reviewed. The nature and structure of the interview was outlined. Participants were asked to sign a consent form (Appendix 7) agreeing to take part in the research and for the interview to be audio-tape recorded. One copy of the consent form was left with the participant and one retained by the researcher as a record. Permission was sought from the participants' for their GPs to be informed of their involvement in the study, as requested by the NREC. A copy of the letter sent to GPs is given in Appendix 8.

Following the interview the participant was thanked for their time and contribution to the research. They were then asked if they would like to receive a transcript of the interview to check, amend and return; whether they would like to receive a summary of the results to comment upon and return and whether they would like the audio-tape returned to them at the end of the study. Field notes were written immediately following the interview.

The audio-tapes were transcribed verbatim by an experienced transcriber. These were then checked for accuracy by listening to the tapes and reading through the transcripts a number of times. Individual transcripts were then sent to those participants who requested it in order for them to check the transcript for accuracy, make any amendments and return. Data were analysed thematically using the framework method described by Miles and Huberman (1994). Computer-Assisted Data Analysis Software (CAQDAS), specifically NVivo 7, was used to aid this analysis. A summary of the results (Appendix 9) was sent to participants to comment upon and return.

#### **4.1.2 Sampling and recruitment**

The population from which the sample was drawn was considered to be all those patients with heart failure registered to one of the three PCT heart failure services. In relation to the inclusion and exclusion criteria, only patients diagnosed with heart failure were included. Diagnosis had been previously determined by the patient's GP or hospital consultant before referral to the heart failure services. No distinction was made between

different types or causes of heart failure and participants with co-morbid conditions were also included. Those patients newly diagnosed and those with long-standing heart failure were included since the purpose was to gain as wide a variety of patients with heart failure as possible.

A number of exclusion criteria applied. Those unable to read or speak English were excluded as written information was not available in other languages. No translation or interpretation services were available so the interviews could not be conducted in other languages. Whilst this was not desirable in terms of equality of access, it was deemed unavoidable given the resource constraints of the study. The HFNs were also asked to exclude any patients who, in their view, were too ill to take part in an in-depth interview. Hence, those with the greatest severity of illness may have been excluded which may have implications for the findings.

A non-probability, purposive sampling strategy was used. In purposive sampling, individuals are selected on the basis of their experience of the phenomenon to be investigated (Silverman, 2010). Sampling was purposive in terms of age and gender so that the views of both men and women from a range of age groups were sought. This was achieved by asking the HFNs to purposefully select participants from these groups. The intention was to select a sample to provide rich, dense description of the phenomenon (Denzin and Lincoln, 2005). Given the higher prevalence rates of heart failure in older age groups and amongst men (NICE, 2010), it was likely that, as a result of this sampling strategy, the sample would include a higher number of females and younger patients than would be typical of the general heart failure population.

In terms of sample size, qualitative researchers vary widely in their recommendations. Authors advocate selection of a qualitative sample size based on time-constraints, the nature of the phenomenon under investigation, the nature of the sample or the concept of data saturation (Silverman, 2010). Time-constraints, whilst relevant to any research, were not in themselves, considered to be adequate justification for the sample size in this study. In relation to the nature of the phenomenon, Morse (1991) suggests at least six participants are needed where the aim is to understand the essence of experience. Lay beliefs and self-care in heart failure have been explored by qualitative researchers with sample sizes of between six and twenty. From a previous study, a sample size of ten was found to be sufficient to explore a similar phenomenon of illness representations and behaviour in MI patients (MacInnes, 2006). In relation to the nature of the sample, Holloway and Wheeler (1996) suggest that between six and eight participants are needed



for a sample with homogenous characteristics while twelve to twenty is required for a heterogeneous sample. In this research, the sample was considered to be relatively homogenous in terms of the illness experience so a smaller sample size was anticipated.

The concept of data saturation means that rather than determining a specific sample size *a priori*, on analysing the data, repetition and confirmation of previous findings determines the end point of data collection (Denzin and Lincoln, 2003). However, the concept of data saturation as an achievable aim is contentious. Miles and Huberman (1994) suggest that since analysis involves peeling away different layers of data to reveal deeper understanding, it is difficult to determine an endpoint. Morse (1991) also cautions that data saturation is both time and context dependent so that new data may be revealed with the same or a different sample at a different time. Although the use of data saturation may be imperfect, seeking repetition and confirmation of findings is believed to enhance the trustworthiness of the findings (Denzin and Lincoln, 2003), hence, this process was used in determining sample size in this study.

Based on the nature of the topic and sample, in this study, a sample size of between six and twenty was estimated, with the final number being determined by data saturation. It was proposed that participants be approached in cohorts of 30 so that an estimated response rate of one third would enable ten participants to be recruited at a time. De Vaus (1996) suggests that in a specialised sample, a response rate of one third might be expected. Following data analysis, this recruitment process could then be repeated as necessary to the point of data saturation.

Initially, an attempt was made to recruit participants by postal invitation. Site C, which was ready to proceed with data collection earliest, posted the envelopes to patients identified according to the inclusion and exclusion criteria. No date was given by which patients should reply, except to request it was returned within two weeks of receipt of the letter. Unfortunately, no responses were received. The reasons for this are speculative although it is suggested that the unsolicited postal method of recruitment might have resulted in this lack of response as this method typically results in a lower response rate (De Vaus, 1996). In addition, the lack of a specific deadline by which to reply may have negatively affected the response in that return of the envelopes may have been put off indefinitely.

It was therefore, necessary to change the procedure by which participants were recruited. It was agreed with the HFNs that they would deliver the envelopes by hand to potential participants, either during home visits or at clinics. Personal introduction is suggested by De Vaus (1996) as a useful technique for improving response rates. In addition, a specific

return date was given on the participant information letter. The revised letter and reply slip are given in Appendix 10. Site A delivered the first 30 envelopes. Twelve participants responded indicating their willingness to take part. This represented a response rate of 40% which is in line with that suggested by De Vaus (1996).

Following collection and analysis of the data, saturation was believed to have occurred so no further interviews were conducted and this therefore, represented the final sample. The implication of this was that, in being drawn from one geographical area (PCT), a less diverse sample may have been selected than if participants were recruited from all three sites as originally proposed.

#### **4.1.3 Data collection methods**

While other qualitative methods are recognised such as focus groups or observational studies, interviews have the advantage of allowing in-depth exploration of the lived experience of people whilst also being practical to organise and conduct (Silverman, 2010). Given that the focus of the research was on individual beliefs and experiences, rather than collective responses, one-to-one interviews seemed most appropriate. A semi-structured format was used as it allowed phenomenon to be explored in-depth but remain focused on the topic under investigation (Fontana and Frey, 2005).

Interviews took place in the participants' own homes in order to reduce any inconvenience, especially to those who may have been elderly or in poor health. This environment was also considered most appropriate to discuss the day-to-day experience of living with heart failure.

An interview schedule (Appendix 11) was developed based on the components of the CSM and self-care literature. This served as a topic guide to enable all relevant areas to be addressed and helped maintain consistency between interview cases so that cross-case analysis could be carried out. Silverman (2010) emphasises that the schedule should be used only as a guide as departures are both necessary and desirable. The interview schedule was checked to ensure that leading questions, which might influence responses, were avoided. The schedule commenced with some simple introductory questions in order to obtain demographic details, for example, *'How old are you?'* These questions were largely closed, factual and easy to answer. The intention was to put the participant at ease and begin the development of rapport. Open questions followed in relation to illness representations, emotional responses, beliefs about medication and self-care. For example, *'What do you understand is wrong with your heart?'*, *'How does your illness make you feel?'* and *'What do you do to care for yourself at home?'* The interview

schedule generally guided the order in which topics were discussed. However, if a participant brought up a topic at an earlier point in the interview, this was discussed at that point so that a conversational style was retained. In this way individuals were encouraged to tell their own personal stories or narratives (Oakley, 1993). However, sometimes it was necessary to gently re-focus the discussion on the topic if it was felt that the relevance of the conversation in relation to the aims of the research was being lost. For example, phrases such as '*Thinking again about your heart in particular...?*' were used. Probing questions were used to follow up responses to more general questions. For example, '*Does your illness change or stay the same?*' '*In what way?*' '*Why do you think this is?*' This technique of using probing questions is advocated by Bryman and Burgess (1994).

In terms of epistemology, the nature of the relationship between the researcher and the participant is important (Denzin and Lincoln, 2005). In this qualitative phase, a largely subjective relationship was apparent. Denzin and Lincoln (2005) recognise that it is neither realistic nor desirable to remain an objective outsider or observer when the aim is to encourage participants to speak openly. Oakley (1993) identifies a traditional interview approach where the researcher asks standardised questions of the respondent whilst refusing to give any personal information about themselves or allow any questions, in an effort to be objective. This denies the complex social interaction that occurs in the communication between the researcher and participant and lacks the acknowledgment that personal characteristics of age and gender, for example, influence the dynamics of the interaction.

Holloway and Wheeler (1996) describe a need for reflexivity or self-examination by the researcher in terms of their own assumptions and values. It requires thoughtfulness and reflection on the relationship with the participant and reactions towards them. The researcher's age, gender, culture, personality and life experience also affect the research process and such influences or 'biases' need to be recognised and acknowledged. However, it has been argued that these influences sensitise the researcher to the events and people in the investigation and can, therefore, be a resource as long as researchers are reflexive and aware of their own assumptions (Olese, 1994).

As a female nurse with a young family, I was aware of the different nature of the relationship between, for example, myself and the elderly gentlemen in the study and the young mother, with whom I perhaps had greater empathy. Also, having knowledge of heart failure and having read the literature on beliefs and self-care, I may have had pre-conceived ideas and expectations about the findings. An awareness of health damaging

behaviours such as smoking or intentional non-adherence to medication, for example, may also have made it difficult to be totally non-judgemental.

According to Holloway and Wheeler (1996), health professionals' own assumptions can interfere with the study as they may feel they know the problems that patients' experience which prevents them from focusing on the patient's real concerns; a point acknowledged in this research. From previous experience of qualitative interviews, in introducing myself as a nurse, participants frequently regarded the interview as a clinical consultation by handing over their drug prescriptions and asking me questions about their health. In this research, I wanted to avoid this in order to try to get beyond ideas about the medically-defined disease into lay beliefs and experiences. This seemed more likely if I could also be identified as a 'lay person' in some way. However, despite this, participants still sometimes asked me clinical questions about their heart failure to which I would refer them to their HFN as professionally, I did not have access to their clinical notes nor did I want to influence their responses. In this way, whilst the subjective nature of the interview was recognised, attempts were made to minimise

The use of field notes are a mechanism whereby experiences, feelings and thoughts are written, which in themselves become objects of reflection. In this study, immediately following the interview, field notes were written. An excerpt of which is given in Appendix 12. Hammersley and Atkinson (1983) suggest that field notes are a central research activity, enhancing the quality of the project. Schatzman and Strauss (1973) divide field notes into three areas: observational, theoretical and methodological notes. Observational notes consisted of those events that were primarily experienced through watching or listening. For example, notes on the participants' state of health such as breathlessness, social influences, interruptions such as the telephone ringing or the participant needing to interrupt the interview and emotional observations such as whether participants seemed anxious or depressed. Theoretical notes attempted to develop analytical concepts or make sense of the data as it occurred, for example, the idea that the management of the illness was a shared experience between the patient and spouse originated from the field notes. Hence, new ideas outside the theoretical framework were noted and cross-references were made to previous cases.

Methodological notes were made in an attempt to enhance the quality of the interviews. As well as the use of field notes, the audio-tapes and interview schedule were reviewed between each interview, where possible, to look for missed questions, leading questions or other methodological issues which could affect the findings. In light of this reflection it

was noted that one question, *'How serious do you think your illness is?'* had been omitted on more than one occasion. On reflection, this seemed to be a question that had the potential to cause distress to participants and was perhaps avoided for this reason. A deliberate effort was made in subsequent interviews to address this question which, although thought-provoking, did not seem to cause undue distress to participants.

From the first two interviews and field notes it became apparent that participants would frequently refer to their spouses to seek confirmation of factual information such as time-scales, or clinical details such as medication names. However, spouses would also interrupt at times to give their own beliefs or interpretations, for example:

*What do you think caused your heart problem?* [Res]

*I really don't know* [P3]

*I think, myself, I'm interrupting again, that the move up here was so horrendous, I'm sure this is what did it* [P3, wife].

It was recognised that this could potentially influence findings in that the data may not be accessing patient beliefs but those of their partner. Therefore, in subsequent interviews, if a spouse was present in the room at the start of the interview, it was explained to them that while their views were important, it was necessary to first establish the thoughts and feelings of their partner. At the end of the interview with the audio-tape still running, spouses were invited to add anything that they wanted to say. Although this was at times visibly difficult for both the participant and their spouse to adhere to, it seemed to be effective in focusing the discussion on the patient's beliefs and experiences. However, it must also be recognised that the mere presence of a spouse during the interview may have influenced the participant's responses to some degree. On reflection, in order to reduce this potential bias, it might have been better if spouses had been asked to leave the room during the interview; however, as I was an invited 'guest' in the participant's home, this did not seem to be appropriate. Furthermore, the finding that self-care, especially medication use, was socially influenced was, in part, derived from the observed interaction between the participant and their spouse (discussed in section 4.2.3).

Although the interview technique was reviewed and refined during the process of data collection, it could be argued that pilot interviews would have been useful since conducting a research interview requires considerable skill and experience to develop good techniques (Denzin and Lincoln, 2003). Furthermore, pilot interviews would have enabled the interview schedule to be tested (Silverman, 2010). Although I had some

experience of conducting research interviews, it is acknowledged that pilot interviews may have been beneficial. This is discussed further in Chapter seven.

#### **4.1.4 Ethical considerations**

Consideration was given to ethical issues in this research, as required under the Research Governance Framework (DH, 2005d) and scrutinised by the NREC. As a registered nurse there was also a professional obligation, according to the Nursing and Midwifery Council (NMC) code of professional practice (NMC, 2008), to obtain consent and ensure confidentiality of patient information. The section discusses those ethical considerations specific to this phase of the research.

The ethical principles of autonomy and veracity (truth-telling) underpin the concept of informed consent (Beauchamp and Childress, 2008) which, in research terms, is defined by Denzin and Lincoln (2003, p.89) as *'receiving consent by the subject after having carefully and truthfully informed him or her about the research'*. Informed consent comprises information, voluntariness and comprehension (Beauchamp and Childress, 2008). Here, written information was given in the participant information letter and discussed at the time of the interview. This information consisted of the nature and purpose of the research, the procedures involved and the potential risks and benefits, how the individual was selected, the identity of the researcher and sponsor organisation and the mechanisms for the dissemination of findings. A minimum of two weeks elapsed between the participant being invited to participate and informed consent being sought at the time of the interview. This was believed to be sufficient time for the participant to consider the information and make an informed choice. That taking part in the research was voluntary was explained by the HFNs on introduction, written in the participant information letter and discussed at the time of the interview. It was stressed that refusal to take part would not affect the care received in any way. Participants were advised that they could withdraw at any time and no monetary or other award was offered. However, it could be argued that since participants were recruited directly by the HFNs there may have been an element of wanting to please the nurse who was known to them and whose care they were receiving. Cognitive impairment is a recognised, prevalent feature of heart failure (Cowie et al, 1999). Therefore, the ability of individuals to comprehend the information and give informed consent needed to be considered. Since the HFNs were asked to select individuals who were suitable, in their view, to take part in the research, there is an assumption that only those able to give informed consent were approached. Although no formal assessment of mental capacity was made, all participants appeared

able to understand the information given to them by responding to questions appropriately.

Research should also ensure that all individuals in society have equal access and opportunity to take part. That is, no group is excluded on the basis of gender, age, ethnic origin, socio-economic status, disability or other criteria (Beauchamp and Childress, 2008). Here, applying the exclusion criteria meant that those unable to read and write a sufficient level of English were excluded, thus potentially compromising equality of access based on ethnic origin.

Privacy, anonymity and confidentiality are related ethical concepts. Privacy refers to the right of an individual to decide the time, extent and circumstances under which they will share information (Guillemin and Gilham, 2004). As some interviews were conducted with family members present and consent to this was not expressly sought, it remains an assumption that this was with the participants' agreement, so maintaining privacy. Anonymity requires that individuals, their families and organisations cannot be identified in the research. Participants were informed in writing that they would not be able to be identified in the write-up of the study or any other publication. The names of family members and other identifiable data such as the names of GPs and local hospitals, have therefore, been omitted.

Confidentiality requires that information and data relating to the individual and their family will not be shared with any third party without their knowledge or consent and that the data will not be used for any other reason than for the research. Only the researcher's supervisor was made aware of participant names, addresses and the date and time of the scheduled interviews. This was necessary to safeguard the researcher as discussed below. This information was destroyed following completion of the interviews. The transcriber also necessarily, had access to the names and some personal identifying data as recorded on the audio-tape. The tapes, transcripts, and other identifying documents were stored in a locked cabinet. Data stored electronically included the transcripts and analysed data. In this case, access was password protected. All data, including the remaining audio-tapes will be destroyed at the end of the study according to University regulations (CCCU, 2006).

Non-maleficence or the ethical principle 'to do no harm' is perhaps the over-riding ethical consideration in research (Beauchamp and Childress, 2008). The potential for harm must be minimised and any risks made clear to participants. In recognition of this, the HFNs were asked to exclude those who were, in their view, too ill to take part in an in-depth

interview. This minimised the potential for physical and psychological discomfort in those most vulnerable. Participants were also informed that they could contact a named HFN following the interview if they had any concerns or worries as a result of taking part (Appendix 13). It was anticipated that some participants might become distressed during the interview when talking about their illness. Some participants were visibly saddened during the interview and were empathetically listened to and given time to express their feelings. One participant became very distressed and cried on a number of occasions. At these points I offered to turn the tape-recorder off and allowed time for them to feel able to continue.

Given the unpredictable and often severe nature of the illness, there was a possibility that some participants might die in the period following the interview before the transcripts, results or tape-recordings were returned to them. Clearly, it would be inappropriate and upsetting for the family if correspondence addressed to the participant was sent to them at this time. To avoid this, the HFNs were asked if it was still appropriate to contact the participant before any further correspondence was sent. This safeguard did, in fact, prove to be necessary as one participant died within two months of the interview. As a result, no further correspondence was sent and potential distress to the participant's family was avoided.

The safety of the researcher was also of paramount importance. A small, potential risk was identified in visiting participants in their homes. This risk was either from the individuals themselves or more likely, the environment or neighbourhood. To minimise this, the HFNs were instructed to only select individuals and areas they themselves would be willing to visit. Visits were only carried out during daylight hours. The researcher's supervisor was made aware of the time and location of the scheduled visits and the researcher telephoned a family member when going into and leaving the participants' homes.

Related to non-maleficence is the ethical principle of beneficence or 'doing good'. That there was likely to be no direct benefit to the participant by taking part in the research was explained in writing, in the participant information letter. However, it is suggested that some participants might welcome the opportunity to talk about their experience of living with their illness and so may have received some benefit. A point acknowledged in qualitative research (Silverman, 2010).



#### **4.1.5 Data analysis**

Computer Assisted Qualitative Data Analysis Software (CAQDAS), specifically the software package NVivo 7, was used for data analysis having first undertaken training in its use. NVivo 7, rather than alternative packages, was chosen simply due to convenience as it was the only software licensed to the University at the time and so was easily accessible. Transcripts with accompanying field notes were loaded into NVivo 7 as individual cases in preparation for analysis.

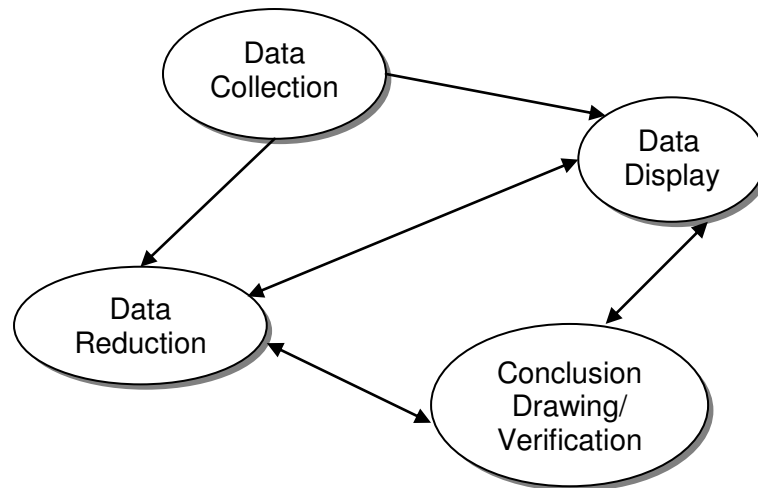
The decision to use computer software was primarily based on the opportunity to make data management easier. From previous experience of qualitative data analysis, the practical management of interview transcripts, field notes, rough notes and ideas, memos and conceptual maps is often difficult, involving unwieldy piles of paper which require frequent sifting and re-organising. Bazeley (2007) identifies data management as one of the principal reasons for using CAQDAS and argues that by removing the laborious process of cutting, labelling and filing there is greater freedom to develop ideas as there is greater opportunity to reconceptualise data (Bazeley, 2007). Certainly, the ease with which segments of data could be grouped and re-grouped made data analysis easier.

Bazeley (2007) also suggests that the use of software helps to ensure rigour through the ability to query the data so that every recorded case of a term or every coded instance of a concept can be retrieved. It is further suggested that the researcher works more methodically, more thoroughly and more attentively. In practice, this enhanced ability to analyse the data in a systematic and methodical way meant there was greater confidence that the data had been thoroughly interrogated. However, whether greater depth of analysis was achieved by using CAQDAS is difficult to judge.

On reflection, although the use of NVivo 7 required an initial, substantial investment of time in learning its use, this was justified by the ease with which data were subsequently managed and reported. However, the instrument of analysis remains the researcher, that is, the computer does not do the analysis for you! The method of analysis must be established beforehand (Bazeley, 2007), as discussed below.

A framework of qualitative data analysis based on that described by Miles and Huberman (1994) was used. This framework was selected because it clearly articulates the decision-making process and procedures in thematic, qualitative analysis. These authors describe three concurrent activities: data reduction, data display and conclusion drawing and verification, illustrated in Figure 4.2.

Figure 4.2 Components of Data Analysis (Miles and Huberman, 1994, p.12)



Data reduction concerns making analytical choices about which data to extract, code and summarise. According to Miles and Huberman (1994), data reduction sharpens, sorts, focuses, discards and organises data. Data display is the organised presentation of information that enables conclusions to be drawn. In common with much qualitative research, data display, here, is in the form of extended text. Drawing conclusions and verification consists of proposing explanations for and evaluating findings in a discussion of the results. These processes are inter-related in that the researcher moves between data reduction, display and conclusion drawing throughout the analysis. The process of data reduction, specifically coding, is discussed below, followed by an integrated display and discussion of the results.

In data reduction, codes are described as abstract constructs that are identified before, during and after data collection. The process of coding as the search for contextual meaning has been described as '*the heart and soul of whole-text analysis*' (Miles and Huberman, 1994, p. 171). These authors differentiate between analysis of 'words or phrases' using techniques such as word counts and analysis of 'chunks' of text in which the contextual meaning is important, as in this study.

Miles and Huberman (1994) suggest that researchers start with some codes derived from the literature or theory and add codes and sub-codes during the process of analysis. They describe a method '*partway between a priori and inductive approaches, that of creating a general accounting scheme for codes that is not content specific but points to the general domains in which codes can be developed inductively*' (Miles and Huberman, 1994, p.61). This supports a pragmatic approach to data analysis, which allows freedom to work between an interpretivist and positivist/postpositivist epistemological position in terms of

deductive and inductive reasoning. Fereday and Muir-Cochrane (2006) also support a hybrid approach of inductive and deductive coding with data and theory-derived code development.

Analysis was theory driven in that themes were developed deductively according to the CSM and self-care literature, that is, illness representations, emotional response, treatment beliefs and self-care were set up *a priori*, as 1<sup>st</sup> level themes. Individual illness representations, treatment beliefs and self-care behaviours, such as identity, concerns about medication and adherence to medication were set up as 2<sup>nd</sup> level themes. Themes also 'emerged' or were inductively derived from the data, for example, impact of medication use on lifestyle was identified as a 2<sup>nd</sup> level theme within treatment beliefs. In this way the theoretical framework was tested for its applicability in this sample.

Coding was a mixed strategy of both within-case and between-case analysis. That is, efforts were made to develop themes that cut across cases or were common to a number of participants, as well as retaining the complex, narrative of each individual case, as illustrated in section 4.2.5.

The process of coding requires that codes be assigned to marked text. It, therefore, required making choices about the meaning of any section of text. Here, each case was initially coded separately before looking for cross-case comparisons. Where codes were already set up according to the theoretical framework, text relating to that code was assigned, for example: *'My breath gets short, I just got a job to breathe'* [P1], was coded as *Illness Representation>Identity> Symptom*. Where codes were developed inductively from the text, the development of new codes and marking text occurred concurrently, for example: *'I'm not saying I'm always optimistic, but I hold on to that'* [P6] was coded as *Self-care > Management > Positive Attitude*, where positive attitude was a code derived from the data.

Codes therefore, acted as tags for marked text as well as theoretical constructs. Consideration was given to the labelling of codes so that their name was as close as possible to the concept it was describing, for example, the explicit code *'support from counsellor'* was used. Miles and Huberman (1994) describe a number of different types of code. Descriptive codes, or first level analysis, entail little interpretation and attribute a simple phenomenon to a section of text. For example, *'The chest pain is so excruciating, I can't move'* [P11] was coded under identity as *'symptoms related to other cardiac conditions'*. Data were also assigned to more interpretive codes which conveyed more complex meaning. For example, *'If I feel tired I can always sit, I can always relax, but*

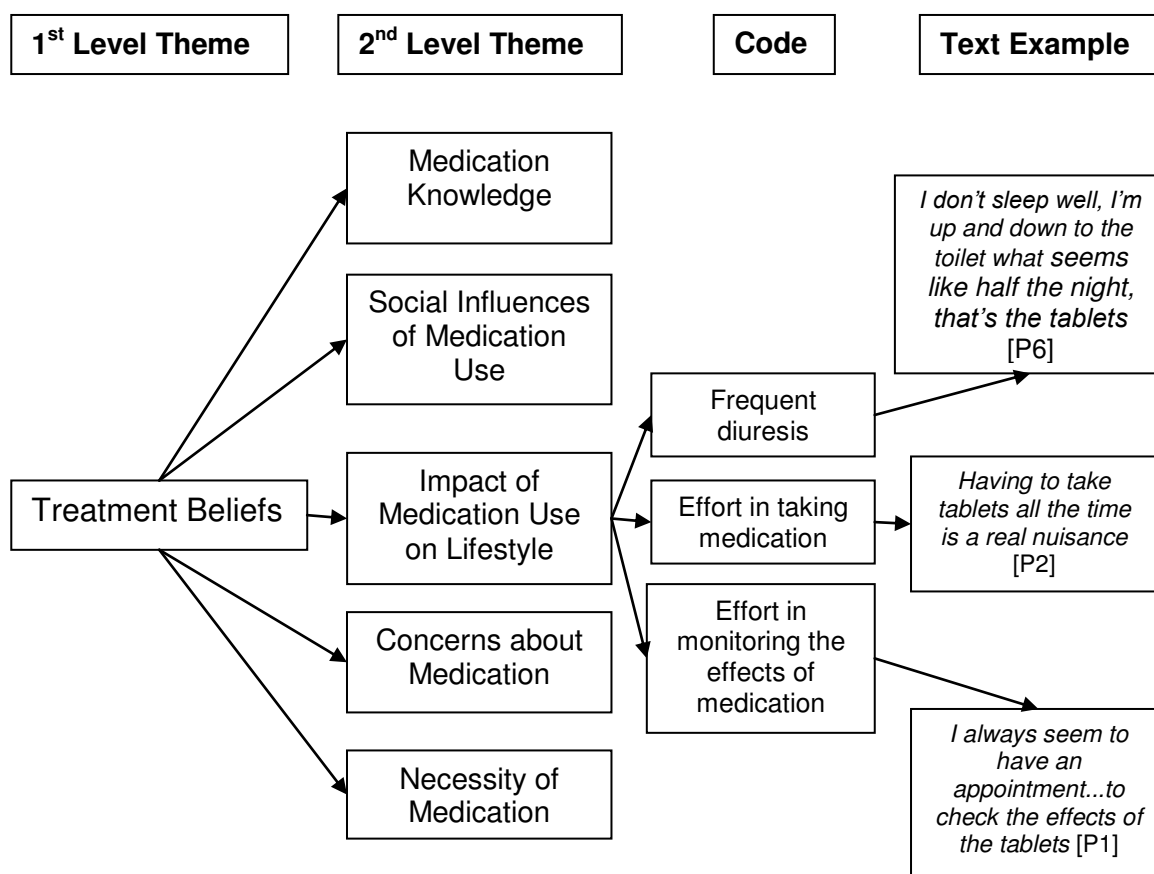
*when you are with friends you can't do that. If I go to my friend's house, it's not nice to go there and fall asleep' [P10]* coded as '*reduced social contact as a consequence of symptoms*', in the illness representation of consequences. Pattern codes group codes into a set of themes or constructs. According to Miles and Huberman (1994) these develop the cognitive map, forming an integrated system for understanding the phenomenon and interactions. For example, the theme treatment beliefs ultimately described a set of five inter-related themes of necessity, concerns, medication knowledge, social influences on medication use and impact of medication use on lifestyle.

Codes and themes were organised into a hierarchical structure. This structure or 'codebook' according to Ryan and Bernard (2003) includes a detailed description of the code or theme, its boundaries, and examples of text associated with it. For example, the theme '*cause*' was labelled and described as '*perceived cause of heart failure*' in order to distinguish it from causes of other conditions, with an example: '*I wonder whether the fact that they put me on steroids for the asthma, whether it started it off*' [P12].

NVivo 7, uses the term 'node' rather than code and differentiates them into 'tree nodes' describing codes organised into an hierarchical structure and 'free nodes' which identify a code which has not yet been incorporated into this structure. Thus, data analysis progressed by codes being grouped together to develop themes which were further split or merged as analysis proceeded. Figure 4.3 gives an example of the hierarchical structure of the 1<sup>st</sup> level theme, treatment beliefs.

Memos were also used as part of the process of data reduction. Glaser (1978) defines memos as '*the theorizing write-up of ideas about codes and their relationships as they strike the analyst whilst coding, providing a little conceptual elaboration*' (p.72). NVivo 7 has the facility to write memos concurrently whilst coding and attach them to segments of text. Miles and Huberman (1994) advise that '*when an idea strikes, stop coding and write the memo!*' (p.72). For example, this memo, written concurrently whilst coding, described ideas about coherence, relating to a marked section of text: '*Lack of coherence perhaps due to difficulties in determining the identity of the illness - what the illness actually is and how symptoms relate to this. Co-morbidities seem to add to the confusion*'. Memos were revisited in the process of developing themes.

Figure 4.3 Example of the Hierarchical Coding Structure



The field notes were also included in the development of codes and themes. According to Denzin and Lincoln (2003) field notes serve to strengthen coding by pointing to deeper or underlying issues. For example the field note, '*P11 found it really difficult to answer questions about his illness and referred constantly to his wife for information and confirmation of his ideas. The illness seems to be very much a shared experience*', helped develop ideas about social influences on beliefs and behaviour.

Arguably, coding is complete when all incidents can be readily classified, categories are 'saturated' and sufficient numbers of regularities occur (Denzin and Lincoln, 2003). No new codes or themes were added beyond the coding of Case 9, although additional examples of codes were found. It was decided that within this sample and context, data saturation had occurred and no further data were collected beyond the initial twelve interviews.

#### 4.1.6 The extent to which the data are trustworthy

Rigour is an important concept in qualitative research. Quantitative data are subjected to tests of reliability and validity. In qualitative data these terms are replaced by the concept

of 'trustworthiness' (Guba and Lincoln, 1995). Trustworthiness is said to exist when the findings of the qualitative study represent reality. Four criteria are proposed for establishing trustworthiness – credibility, transferability, dependability and confirmability.

To establish credibility, participants need to be identified and described accurately. The characteristics of the sample are discussed in the following section. A further aspect of credibility is the use of member checks or the practice of allowing participants to check the findings to make sure they are true to their experience. Although this was attempted, few participants chose to make further comments beyond the initial interview. This may have been because participants were completely happy with the accuracy and interpretation of the data. However, what seems more likely is that participants were not particularly interested in contributing further to the research, which is a common experience according to Bryman and Burgess (1994). Participants seemed to be most interested in receiving the results in order to find out the extent to which their experience was similar to or different from that of others, rather than wanting to add further comments.

Transferability is the degree to which findings can be transferred from the sample to the population as a whole. Since purposive sampling was used in this phase of the study, transferability was not a prime consideration. However, Holloway and Wheeler (1996) suggest that as long as the characteristics of the sample are described accurately and a clear decision trail is given in relation to data analysis, readers themselves can determine if the results can be applied to their own setting. In order for the research to be dependable, again a clear decision trail should exist, where theoretical and methodological choices are discussed throughout. Confirmability links the source of the data through to the conclusions. In this study, quotes from individual participants are linked to identified themes which are then used in the adaptation or development of the questionnaires (Chapter five) and considered in an overall discussion of the results (Chapter seven). By following these criteria it is anticipated that the results of this phase of the research may be considered trustworthy.

## **4.2 RESULTS AND DISCUSSION**

This section presents the results and discussion of the interviews. First, the characteristics of the sample are described before discussing the findings in relation to published literature and the CSM.

### **4.2.1 The Characteristics of the Sample**

The characteristics of the sample are presented in Table 4.1.

**Table 4.1      Characteristics of the Interview Sample**

	<b>Number of Responses (n)</b>	<b>Range</b>	<b>Mean</b>	<b>SD (±)</b>
Age (years)	12	37-85	70.08	12.84
Time with Illness (years)	12	<1-15	4.16	3.85

	<b>Number of Responses (n)</b>	<b>Frequency</b>	<b>%</b>
Gender	12		
Male		7	58.3
Female		5	41.7
Ethnic Origin	12		
White, British		11	91.6
White, Other		1	8.4
Social Situation	12		
With partner/family		9	75.0
Lives alone		3	25.0
Qualifications	12		
None		9	75.0
GCSE/O'Level		3	15.0
Occupation	12		
Retired		11	91.6
Employed		1	8.4
Co-morbidities	12	12	100.0

Seven men and five women were interviewed. This represents slightly more women than would be expected in the heart failure population as a whole with national prevalence rates of 3.0% in men and 1.7% in women (Davies et al, 2001). The mean age was 70.08 years (SD ± 12.84, range 37-85) although younger participants were represented. That most participants were from older age groups is consistent with the disease trajectory (Cowie et al, 1999). The purposive sampling strategy can, therefore, be considered successful in meeting the intended aim of recruiting men and women from a range of age groups.

All participants were of 'White, British' or 'White, Other' (in this case, Western European), ethnic origin as defined by the Office for National Statistics (ONS, 2008). No participants were drawn from Black Minority Ethnic (BME) groups which, given that the population in this locality is predominantly white (94%) with only 6% of the population of BME origin (KCC website 2008), might be expected. Similarly, the proportion of BME patients with

heart failure in the locality is estimated to be only 6% (PCT heart failure service databases, 2010). Caution should; however, be exercised in extending conclusions to other ethnic groups.

Nine participants lived with their spouse or family with three living alone, all of whom were women. Few participants ( $n = 3$ ) had formal qualifications at GCSE/'O' level equivalent or above. Most participants were retired which again, would be expected in these age groups. Only one participant was in paid employment but had not returned to work following the onset of her heart failure. Participants had been living with heart failure for an average of mean 4.16 years (range <1-15 years,  $SD \pm 3.85$ ). All participants had co-morbidities, most commonly CHD which might also be expected since CHD is three times more common in those with heart failure (Thomas and Velaquez, 2005).

#### **4.2.2 Illness representations and emotional response**

Illness representations comprise beliefs about illness identity, cause, timeline (acute, chronic or cyclical), consequences, the extent to which the illness can be cured or controlled (personally or through treatment) and coherence. According to the CSM, illness representations and the emotional response to the illness are processed in parallel hence emotional response is also discussed here.

#### **IDENTITY**

The identity domain is composed of an understanding of the nature of the illness, the diagnosis or 'label' attached and associated symptoms (Cameron and Moss-Morris, 2004). In terms of the nature of the illness, differentiating heart failure from other cardiac conditions was difficult:

*I collapsed in the doctor's surgery and they rushed me into hospital and I had a pacemaker fitted [P6]*

*I've got a couple of blocked arteries and I've got one that's OK [P5]*

These examples seem to describe an arrhythmia and CHD, respectively, rather than heart failure.

The symptom of breathlessness was frequently attributed to an acute or chronic respiratory condition which may have been due to an inability to correctly identify breathlessness as a symptom of heart failure or could describe the presence of respiratory co-morbidities. For example:



*My problems are not my heart. I don't feel that my heart is a major problem. Obviously, you get to a position, which for medical reasons, they call chronic heart failure and I've no doubt reached that stage but my problem is that I'm very prone to getting pneumonia [P1]*

*I get puffed out because I've got asthma [P6]*

For one participant, a number of labels made identifying the illness difficult:

*It was 'left ventricular systolic dysfunction' then I got a letter saying 'dilated cardiomyopathy, ischaemic heart disease' and I thought 'that's a bit different from what I've heard' [P8]*

Differentiating symptoms, the effects of medication and the emotional response to the illness was also problematic:

*I've got no appetite now, eating is just something that has to be done. I still don't know the cause of that. I know the digoxin made me continuously nauseous with no appetite but the digoxin has been stopped and I still haven't got the appetite. I don't know why [P11]*

*I get light-headed, dizzy sometimes. I don't know if I get a few panic attacks. I don't know if it's the panic attacks I'm getting or if it's to do with the medication or the condition. Probably after I get the feeling, I do panic but I don't know if it's the actual condition that's giving me the funny turn [P8]*

The hope that greater experience of the illness would improve understanding was expressed by one participant which suggests that greater length of time with the illness may be related to a clearer illness identity:

*It's a new learning thing for me. Maybe in a few years I'll think, 'oh, I know this is to do with my heart condition, or medication or whatever' [P8]*

Where heart failure could be differentiated from other conditions it was described in terms of the heart not pumping blood effectively:

*The problem is the heart won't pump blood fast enough. The walls are weak so they're not pumping the blood [P3]*

*I would say my pump doesn't work 100%, like normal people. I've got a bit less pumping action. The left ventricular side of my heart, that's a bit like jelly [P8]*

This is broadly congruent with the biomedical view of heart failure although most participants were unable to define their condition in this way, referring largely to the symptoms and their effects.

In summary, identifying the nature of the illness was difficult for most participants. This may have been due to the presence of other illnesses particularly other cardiac conditions, changing labels or diagnosis and difficulties differentiating symptoms from the effects of medication and emotional responses. Where heart failure could be identified it was most commonly described in terms of the heart's failure to pump blood effectively. The difficulty in connecting symptoms of heart failure to the condition was also found by Horowitz et al (2004). Similarly, Rogers et al (2002) found that symptoms were frequently attributed to the effects of medication.

The symptoms of heart failure were described, in order of frequency, as breathlessness, tiredness and daytime sleepiness, sleep difficulties, dizziness or light-headedness, forgetfulness, loss of appetite, cold fingers and toes and sexual difficulties. The number of symptoms varied with most participants describing at least three symptoms.

Depression was frequently described and could be categorised as a symptom, emotional response, consequence of the illness or co-morbidity. In this analysis, depression is discussed in terms of the emotional response as this was the context in which most participants described it. Similarly, tiredness and sleep difficulties could be conceptualised as either a symptom or a consequence of the illness. As both are recognised symptoms of heart failure in the literature, they have been categorised as such.

All participants described breathlessness:

*My breath gets short. I've just got a job to breathe [P6]*

*I'm a little bit breathless but only if I go upstairs carrying things [P9]*

Tiredness and daytime sleepiness were also frequently described:

*I get tired, sometimes very tired. I get tired very easily [P10]*

*The thing I do suffer from now is tiredness. I never used to sit down in the afternoon, now I have to sit down and have a nap for half an hour, 45 minutes [P12]*

Difficulty sleeping at night was also commonly associated with the illness:

*I can't sleep. I have to have three pillows now. I can't sleep flat. My sleep pattern is completely a sham. I can have a night when I'll go to bed and fall asleep straight away and the other night I was awake until 4 o'clock in the morning [P8]*

*I haven't slept in a bed for about five years because if I lie down flat I can't breathe. I gave up in bed and now I just sit in a chair [P1]*

Dizziness and light-headedness:

*It's a funny feeling in your head. It's like a drained feeling and you tend to lose your balance. My head is all over the place [P3]*

*Sometimes when I'm walking, I just feel like I'm going to pass out. I just feel really funny, really light-headed and floaty [P8]*

Forgetfulness:

*Sometimes even reading a book, I can't remember what I've just read or I can be talking and all of a sudden I think, 'what were we talking about?' [P8]*

Loss of appetite:

*I've got no appetite now, eating is just something that has to be done [P11]*

One participant described peripheral coldness:

*I get blue fingers, white fingers, tingling cold toes [P11]*

Sexual difficulties were also described by one participant:

*I'd probably have more sex if I didn't have a heart problem! [P5]*

The symptoms described are broadly consistent with documented heart failure symptoms (Nicholson, 2007). Breathlessness, particularly on exertion is considered to be a classical sign of heart failure (Ahmed et al, 2004; Badgett et al, 1997; Harlan, 1977). Tiredness and daytime sleepiness are non-specific, prevalent symptoms of heart failure but which may be experienced in older age groups and related to depression (Ahmed et al, 2004). Insomnia, orthopnoea and loss of appetite are widely described (Nicholson, 2007; Merritt,

2004) and light-headedness and dizziness are commonly experienced and related to poor cerebral perfusion (Cowie et al, 1999). Cognitive impairment, which may manifest as forgetfulness, is increasingly recognised as a symptom of heart failure with an estimated 30-50% of heart failure patients having some degree of deficit (Leventhal et al, 2005). Although sexual dysfunction has been reported in the literature as a symptom of heart failure, this may also be related to treatment or psychological factors such as depression (Nicholson, 2007). A number of these symptoms such as tiredness, dizziness, loss of appetite and sexual difficulties, are recognised effects of heart failure medication particularly beta-blockers, ACEI and diuretics so it is perhaps unsurprising that some patients find it difficult to differentiate symptoms from the effects of medication (Nicholson, 2007).

Interestingly, peripheral oedema, most commonly ankle swelling, which is considered a classical symptom of heart failure (Ahmed et al, 2004; Fonseca et al, 2004; Badgett et al, 1997; Davie et al, 1996; Harlan, 1977), was not identified by participants in this sample. This may be because it was either not experienced, perhaps due to optimal medication management, or it may have been considered of limited consequence or was not recognised as a symptom of heart failure. Paroxysmal nocturnal dyspnoea, also considered to be a specific symptom of heart failure (Merritt, 2004), was not explicitly described in this sample but may have been categorised more generally as sleep difficulties.

## **CAUSE**

Beliefs about causation are considered to be important components of explanatory models of illness, including the CSM. Although causes can be considered individually, beliefs can be grouped into external and internal causative factors. External causes are those perceived to be outside the influence of the individual while those internal are believed to be influenced by personal processes (Leventhal et al, 1997).

Although one participant was unable to suggest a cause:

*I can't think of anything. No idea at all. I've never been ill before. No, I can't think why [P9]*

The belief that the illness was caused by external factors or stressors was prevalent with a minimal role perceived for internal causes. Family history, other illnesses and treatment for other illnesses were identified:

*The only thing I can think of is that my mother died of a heart attack. Her brother had a heart problem so I think it's been passed on like that [P11]*

Other illnesses, including a genetic condition and a virus were cited:

*What do you think caused the problem with your heart? [Res]*

*Pseudoxanthoma elastica [P5]*

*It was down to a viral infection that attacked my heart [P8]*

Two participants believed that their heart failure was due to drugs given to treat other illnesses, namely, cancer and asthma:

*I was told by Dr (name) that the chemo had enlarged it (the heart) and it wasn't working particularly well [P7]*

*For years they'd been treating me for asthma and as things got worse they were increasing the dose of steroids, and, in fact, at the end of the day, I hadn't got asthma, I'd got this heart problem. I wonder whether the fact that they put me on steroids for the asthma, whether that started it off [P12]*

Stress, particularly due to external stressors was commonly viewed as the cause of the illness. According to Lazarus and Folkman (1984) stress is described as an internal process consisting of a stressor (which may be external or internal to the individual), an appraisal of that stressor and a subsequent coping response. In this sample, overwork, a specific stressful event or family conflict were identified:

*Obviously, I'd been abusing myself. I'd been overactive. I've been self-employed all my life and you work at a totally different pace when you're self-employed. You're not a nine-to-five person. I mean, I could be in Cologne at 1.30pm and say, 'I must get back to watch Coronation Street' and you drive all the way, non-stop. Always rushing about and I suppose that's probably the reason [P12]*

*We put the house on the market in the morning and sold it in the afternoon. We had to get out. I was all right before I came here. I think it was the stress really [P3]*

*To be the black sheep of the family as they called me. They don't seem to understand me, it's like I don't fit in with them and I'm not the same family. My health is because of everything to do with that [P10]*

Lifestyle factors were not commonly identified as potential causes of heart failure in this sample. Two participants identified smoking as a potential cause but this was externalised and moderated against a background of environmental factors or stress.

*I think quite honestly it's smoking but I was also working in coal burning ships where you go inside a bunker and you'd be black and the inside of your mouth would be black with coal dust and you're breathing all the dust. You're pulling asbestos apart and the air's full of it so all these things together no doubt, have played some part [P1]*

*I smoke but I'm not blaming the cigarettes for my illness. Partly, yes, but I think it's the stress and the cigarettes as well. I should say 90% was the stress and 10% was the cigarettes [P10]*

In summary, the cause of the illness was attributed to largely external factors such as family history, genetic illnesses, infections, drugs or environmental factors. Although, these agents are medically recognised causes of heart failure (Cowie et al, 1999), they are all relatively uncommon. In the UK, most cases of heart failure are due to CHD with about one-third due to hypertension (DH, 2003). In this sample, nine participants mentioned previous heart attacks, angina, hypertension or interventions for CHD, such as coronary artery bypass grafting (CABG), but did not make the connection between these conditions and their current symptoms or diagnosis of heart failure. That is, they failed to identify CHD as the cause of their illness even though, for most, this was probably the most likely cause according to a biomedical model of the illness. This may be because, as discussed in relation to identity, some participants had difficulty differentiating heart failure from other cardiac illnesses so may have been referring to the cause of their heart problems generally and not specifically heart failure. The influence of lifestyle factors, such as smoking, were minimised within the context of external factors.

This belief in stress as a causative factor was also prevalent and supports the findings of Baumann et al (1989) who argued that the presence of life-stress led people to attribute unusual symptoms to stress rather than to the illness (the stress-illness rule). Stress was found to be the most commonly perceived cause of other cardiac conditions including MI (Petrie et al, 1996) and angina (Furze et al, 2001). In heart failure, Horowitz et al (2004) and Morgan (2008) also found that the illness was frequently attributed to stress.

## TIMELINE

Timeline refers to beliefs about whether the illness is acute and short-lasting or chronic and long-lasting and describes the expected illness trajectory or whether the illness is expected to improve, stay the same or get worse in time. The pattern of illness or whether the illness or its symptoms are cyclical or episodic is also considered a dimension of timeline in the CSM.

Heart failure was most frequently described as a chronic condition which was expected to stay the same or get worse in the future. For example:

*I think it will stay the same or get a bit worse. It won't get any better will it? [P4]*

*It will probably get progressively worse [P5]*

Advancing age was seen as an influencing factor in the progression of the illness:

*Getting old, usually things don't get better. It's like arthritis; it doesn't get better with age does it? If it's the heart that's tired or worn out or failing in whatever way, it's not going to get better [P1]*

Two participants tentatively expressed a belief in an acute illness which might be cured or at least improved. One described an enlarged heart as a result of recent chemotherapy improving while another expressed faith in medication:

*It (the heart) has probably gone back down again now. I think it was enlarged but I think it's improved [P7]*

*These drugs that will strengthen the walls of the heart and do this and do that, if they do what they say they do, then yes, it's got to get better hasn't it? [P12]*

Both participants held strong beliefs about the powerful nature of medication as illustrated by the belief that the heart failure was caused by medication and could therefore, be improved by stopping that medication or by taking heart failure medication.

A number of participants perceived a cyclical or episodic timeline in relation to symptoms and emotional response to the illness rather than the illness as a whole with 'good' and 'bad' days described:

*Well, some days I feel better than others [P3]*

*I get good days and then I get a few bad days [P4]*

Overall, viewing heart failure as a chronic illness which was likely to stay the same or get worse in the future was the most prevalent belief and represents an accurate illness trajectory. This belief is consistent with patient studies by Morgan (2008), Cherrington et al (2006) and Voelmeck (2006) but in contrast to the findings of Horowitz et al (2004) where a prevalent belief in heart failure as an acute condition was described.

## **CONSEQUENCES**

The illness representation of consequences describes the extent to which the illness is believed to have serious consequences and the nature of these, for example, physical, psychological, social and financial effects.

In this sample, the illness was generally viewed as having serious consequences:

*To me, it's very serious. The way I feel, it's bad [P10]*

*I suppose it is serious, really [P9]*

Physical consequences were most frequently described, mostly in relation to poor exercise tolerance and the symptoms of tiredness or fatigue:

*It takes so much effort to get anywhere in the mornings, I haven't got the energy [P2]*

*I used to walk two or three miles a day. I can't do that anymore. I find now I just haven't got the energy. It seems that I've got no energy at all. I mean even walking across the room is not as easy [P1]*

Similarly, carrying out household chores and climbing stairs was problematic, particularly in terms of provoking symptoms:

*If I give a hand to make the bed, if I bend down to tuck the sheets in, then very often I've got to sit down [P3]*

*That's why I came to live here in a bungalow because stairs are very bad for me, I just can't do it. I start to puff, puff [P6]*

For some, physical consequences were moderated by age and exacerbated by co-morbidities:



*I couldn't change a light bulb now, I've got a problem climbing up but I think that's probably something that happens to all 80 year olds [P1]*

*I've arthritic knees, one hip and lower spine and I can't have the operations because of the anaesthetic and my heart, so because of my mobility problems, if my knees and back are too bad, I don't get around the corner [P11]*

Social consequences, specifically reduced social contact due to symptoms was described:

*If I feel tired I can always sit and relax but when you are with friends you can't do that. If I go to my friend's house it's not nice to go there and fall asleep! I used to call my friend and we used to go out. We used to go shopping or go for a meal. Not any more [P10]*

*I can't go out the way I used to. When our little granddaughter was one year old I used to take her out. We used to go all over the place and drive and that, and I just can't do it. The last year or so, I just can't do it. I get too tired [P1]*

Concerns about the reactions of others to the illness were also described by women in this sample:

*I was in a shop one day and I fainted, I just felt funny. I knocked against these two people and they laughed and said 'it's a bit early to be drunk. That woman is drunk!' It did upset me [P6]*

*Other people don't understand. I mean, before I had this, if I'd seen someone in the playground having a funny turn, I'd think, 'Tut! What's she on about!' You do get bitchy people that think, 'Oh God, pull yourself together!' [P8]*

As this view was only expressed by two women in this sample, it is difficult to draw reliable conclusions on the influence of gender in relation to concerns about the reactions of others. However, it suggests that women are more keenly aware of how having heart failure might be perceived by those who are 'well'.

In summary, there was a prevalent belief that the illness had serious consequences, a finding echoed by Cherrington et al (2006) and Voelmeck (2006). Consequences were predominantly physical, although this was viewed within the context of advancing age. A tendency to attribute the effects of illness to increasing age is recognised by Bauman et al (1989) and termed the 'age-illness' rule. In addition, in this sample, negative social

consequences were described in terms of reduced social context and concerns about the opinions and reactions of others. This last finding may be a gender-specific concern as this view was only expressed by women in this sample. Overall, these findings are supported by Mahoney (2001), who described the consequences of heart failure as disorder on physical, emotional and social levels. The Department of Health (DH, 2007) also describe the consequences of living with long-term conditions in these terms.

## **CURE AND CONTROLLABILITY**

Cure and controllability describes beliefs about the extent to which the illness can be cured or controlled and by what means, personally or by treatment. Beliefs about control rather than cure were described, which is consistent with the belief that the illness had a chronic timeline.

For some, a lack of illness control was described:

*The illness controls me, I don't control it [P10]*

*I just have to accept it, there's nothing I can do about it [P3]*

For one participant, this lack of control was related to increasing age and beliefs about the side-effects of the medications:

*They say 'there's nothing we can do about your heart'. My doctor's actual words were 'you're 85, you've got a dicky heart, your kidneys aren't all that clever, so make the most of it!' [P3]*

Where some degree of control over their illness was described, this was most commonly believed to be achieved through the use of medication. This belief seemed to be related to a perceived improvement in symptoms as a result of taking medication.

*I was short of breath but since I came under Dr (name), she's done a lot with my tablets and I'm 50 times better. I've seen a vast improvement through the tablets [P4]*

*I've seen a big improvement with the tablets. I can walk further. I don't get out of breath so much [P11]*

In terms of maintaining personal control, a positive attitude and exercise were seen as important:

*You've got to be cheerful, if you can be cheerful that helps your health a lot. People can help themselves get better. Some people feel sorry for themselves, it's no good. There's always a blue sky to look at. I'm not saying I'm always optimistic but I hold onto that. I think that's the important thing [P6]*

*Exercise controls it definitely. Got to keep exercising every day, keep it working hard. Work your heart hard, it's a muscle, it needs stimulation. My main exercise is the bike. I've got strong legs and I think I've got a strong heart [P7]*

Overall, although lack of control was described by some participants, there was a prevalent belief in treatment control. A degree of personal control was also described and believed to be best achieved through the emotional factor of maintaining a positive attitude and the lifestyle factor of exercising. Other lifestyle factors, for example, a low sodium diet, were not identified as controlling factors. Although lack of control is described by Horowitz et al (2004), Morgan (2008), Cherrington et al (2006) and Voelmeck (2006) found strong beliefs in both personal and treatment control. However, in these studies, the belief in personal control was stronger than treatment control which is seemingly in contrast to the findings in this sample.

## **COHERENCE**

Coherence or beliefs about the degree to which the illness makes sense was difficult to analyse in that, when asked directly, most participants agreed, albeit tentatively, that their illness made sense to them:

*Yes, I think I understand it all, really [P1]*

However, this was frequently not demonstrated in other responses. For example, lack of coherence was demonstrated through an uncertain cause or illness identity:

*I really don't understand much. I can't think why I collapsed in the garden; it's a mystery really [P9]*

*Where the water comes from, I don't know. I don't understand that bit of it [P5]*

*My diagnosis has changed somewhat, so I'm getting a bit confused. When I came out of hospital I thought I had one thing and then they're saying 'no, it might be...' My head's a bit of a buzz. I get puzzled because you get told one thing and then*

*halfway through you get told something else and then you're back to square one again and there are so many technical terms [P8]*

According to the CSM, coherence relates to the belief that the illness makes sense. However, this appears to be a different concept from that of a demonstrated coherent view of the illness in terms of other illness representations. This may explain why in studies using the IPQ-R (Cherrington et al, 2006; Voelmeck, 2006), where coherence is assessed through statements such as '*I have a clear picture or understanding of my condition*', a coherent picture of the illness is reported but in qualitative studies by Horowitz et al (2004) and Mahoney (2001) inconsistencies and misconceptions in relation to other individual illness representations, lead the authors to conclude that there is a lack of illness coherence.

## **EMOTIONAL RESPONSE**

Whilst one participant reported no negative emotions, most participants described one or more feelings of depression, anxiety, panic, loss of confidence, anger, frustration or feelings of guilt.

In relation to depression, this ranged from feeling down or 'fed up' which seemed to be due to poor exercise tolerance, to desperation and suicidal thoughts:

*I feel fed up really. I'd like to do lots of things but I can't [P5]*

*I just had difficulty breathing; no matter what you do you can't breathe. I felt so down and that was not like me. You almost get in a depressive state and I felt as if I was really pushing my luck and I really couldn't see that I could keep overcoming the problem. I mean, it kept coming back and coming back and coming back. I had difficulty to struggle out of it that time [P1]*

*To be quite serious, there've been one or two times when I've thought, 'if I had the guts I'd end this...', but I've not got the guts to do it [P3]*

Anxiety or panic and resulting loss of confidence were also expressed:

*My breath gets short and I've just got a job to breathe so what I have to do is.... I have to stop myself because if you're not careful you start panicking [P1]*

*I have to think before I go anywhere because I think, 'Oh, am I going to have one of my funny turns?' Like my son was at a birthday party and I had a funny turn in there and I had to leave. I've lost my confidence going places [P8]*

*I still haven't walked 18 holes. I probably could do it without any problems but you're a bit wary aren't you, especially in the winter, pulling a trolley [P12]*

Anger and a sense of frustration were also prevalent responses:

*Any little thing will irritate me and I get angry for nothing. Stupid things and I should laugh about it but it just makes me feel angry [P10]*

*I get so frustrated because I was going to do so much [P4]*

One participant reported feelings of guilt:

*I feel guilty with the kids. You've got to say, 'Mum can't do that today', and you feel quite bad. I feel bad for my husband because he's such a good support and he's done everything. I feel bad for him. I'm relying on him a lot and he never moans but I feel bad [P8]*

In summary, negative emotional responses to the illness were frequently and often powerfully described by both men and women of all age groups. Depression is recognised as a prevalent experience of patients with heart failure with at least 11% of heart failure patients feeling depressed (Leventhal et al, 2005). Anxiety and panic have also been described in qualitative studies by Rogers et al, (2002) and Mahoney, (2001). In contrast studies using the IPQ-R report a neutral emotional response to heart failure (Morgan, 2008; Cherrington et al, 2006).

In conclusion, in relation to illness representations and emotional response, there was for many, a lack of a clear illness identity often due to the presence of other illnesses, particularly other cardiac conditions. Differentiating between heart failure symptoms, the emotional response to the illness and medication effects was also problematic. This is consistent with qualitative studies on lay beliefs by Horowitz et al (2004), Rogers et al (2002) and Mahoney (2001). Symptoms described were generally typical of the biomedical view of heart failure with breathlessness and tiredness most frequently experienced. Peripheral oedema and paroxysmal nocturnal dyspnoea, also commonly cited symptoms of heart failure were not described in this sample.

The illness was most commonly attributed to external factors such as family history or stress due to external stimuli. Stress as a causative factor in illness is consistent with the theory of Baumann et al (1989). Lifestyle factors were not generally recognised as causative factors. Although many of the participants in this sample described symptoms of CHD, this was not recognised as a possible cause of the heart failure possibly due to the failure to differentiate heart failure from other cardiac diseases. The illness was commonly perceived as a chronic or long-term condition which was likely to deteriorate over time, which describes an accurate illness representation. This is in contrast to the findings of Horowitz et al (2004) but supported by Cherrington et al (2006) and Voelmeck (2006). Although symptoms were at times, described as coming and going (cyclical), the illness itself was not viewed in this way.

The illness was described as having serious consequences which were predominantly physical, although reduced social contact and concerns about the reactions of others were also described. There was a strong, prevalent belief in the control of the illness by medication with a less powerful role for personal control. This is in contrast to the findings of Cherrington et al (2006) and Voelmeck (2006) where strong, personal rather than treatment control beliefs were most prevalent. Illness coherence was reportedly high in this sample with participants in broad agreement that the illness 'made sense', however, this was not necessarily evident in other illness representations. Negative emotional responses to the illness were widespread with depression and anxiety most prevalent. Depression especially, is well documented in heart failure (Leventhal et al, 2005).

Few differences were observed in terms of socio-demographic characteristics of age, gender, social situation, education level or time with illness. In some older participants, advancing age was seen as a moderating factor in determining the physical consequences of the illness and re-enforced beliefs about a chronic timeline. Concerns about the reactions of others to the illness were only expressed by women in this sample which may reflect a gender-specific finding requiring further investigation.

In applying the CSM as the theoretical framework, the existence of the five illness representations and the emotional response to the illness was supported by the data which could readily be assigned to these constructs. Coherence, described as a meta-cognition by Moss-Morris et al (2002), was more difficult to describe which, it is hypothesised, may be related to the different ways in which this term is used in published studies. No new or additional representations or cognitions were identified from this analysis, rather, heart failure-specific symptoms were highlighted, for example,

'forgetfulness' and 'daytime sleepiness'. Beliefs about causation, for example 'medical treatment for other illnesses' and 'other heart problems' were identified as specific causes of heart failure.

#### **4.2.3 Treatment beliefs**

Treatment beliefs can be seen as an extension of the CSM (Horne, 1997) and comprise beliefs about the necessity of and concerns about treatment (Horne et al, 1999).

### **NECESSITY AND CONCERNS**

Only two participants expressed some doubt about the necessity of their medication:

*I don't know whether they're essential or not because I've been taking them since day one when I came out of hospital [P12]*

*I'd like to stop all of them and see what happens and if necessary come back on them again [P2]*

Most participants held the view that medication was necessary often due to the perception that symptoms improved as a result of taking medication:

*I have to take them because if I didn't take them, I'd probably feel worse than I do now, so I have no choice but to take them [P10]*

*I take them because obviously they do improve my life a lot, they do help [P8]*

*My tablets probably keep me alive [P5]*

Although one participant had no concerns about their medication, most were concerned about drug interactions and side-effects:

*The blood pressure medication is interacting with the chemotherapy which also lowers the blood pressure so basically at one stage, my blood pressure was 80-something over 50-something and I was falling over [P7]*

*It's hard to know what you can take with your medication. When I came out of hospital I had a cold and I took ibuprofen and I don't think you can take that. And Lemsip, on the box it says 'if you have a heart condition or take beta-blockers....' [P8]*

Negative or 'side-effects' of medication were of widespread concern:

*One of them, the water tablets, when they clear out the water they clear out the salt as well and my potassium level was low so I had to take tablets to crack that! [P3]*

*Aspirin. I've got terrible stomach aches with it [P10]*

*I know the digoxin made me continuously nauseous and no appetite [P11]*

*I had this cough, I knew what tablet was doing it [P4]*

*I was on one that caused problems for my liver and I had to stop that and other ones cause other side-effects. I have insomnia, I have all sorts of things really, which you could attribute to the tablets, side-effects of the tablets [P5]*

Information given in patient information leaflets seemed to add to these concerns:

*I'm terrible with the leaflets you get. I read them all and what they can do. One of my tablets, I have to have my kidneys checked because they can affect your kidneys and that's all I need! [P8]*

Concerns about side-effects seemed to be particularly related to higher doses:

*I did ask the doctors to cut down because I was fainting all the time, in the street everywhere. They have reduced the amount and I'm OK up to now. High doses seem to be dodgy to me [P6]*

*I think there is a possibility that the tablets may be too strong for me and that's what's making me feel tired [P12]*

*I'd had these incredibly painful cramps caused by the increase in dose [P12]*

Balancing necessity and concerns was described by some participants:

*With every medicine there is a side-effect and you have to weigh up whether you're being helped or not, considering the side-effects [P5]*

*You have to weigh up how much good the tablets are doing you as opposed to if you've got any problems with side-effects [P1]*

In summary, there was a strong, prevalent belief in the necessity of medication which was seemingly related to the perception of improved symptoms. However, concerns about



drug interactions and side-effects were also widespread. Concerns about side-effects were also found to be important to patients in studies by Riegel and Carlson (2002) and Stromberg et al (1999). Higher doses of medication seemed to increase these concerns, in this sample. Since heart failure medication management includes the practice of up-titration or increasing dosage in a step-wise fashion to a target dose, this finding may be a specific concern in this illness group. Concerns about side-effects also seemed to be increased by reading the patient information leaflets contained in the medication packaging. This was also found by Rogers et al (2002) where higher doses and patient information leaflets added to concerns. A cost-benefit analysis, as described by Horne and Weinman (1999), was found in this study where strong beliefs about necessity were balanced against concerns.

## **MEDICATION KNOWLEDGE**

In addition to necessity and concern beliefs, participants described their perceived knowledge about the actions, doses and timing of medication. As the accuracy of this knowledge was not verified by prescriptions, this theme describes perceived knowledge or the confidence in one's ability to understand the use of medication. In terms of drug actions, most participants were confident in their knowledge. For some, this information was gained from the patient information leaflets:

*Atorvastatin, that's for my cholesterol, the aspirin's to keep the blood thin, atenolol, the beta-blocker, that slows my heart down a little bit and then I'm on a couple of other things – I think there's a water tablet in there as well just to help with fluid retention [P7]*

*I've read up on every one of them, one's for blood pressure, one's for doing this and that. I've actually gone through all those papers [P8]*

In contrast, one participant did not believe they had a clear understanding of the actions of their medication:

*I wake up in the night because I'm going to the toilet all the time and then I go back to bed and lay there and think, 'I'll make a cup of tea'. I don't think any of my tablets are what they call water tablets, I don't know what water tablets are, whether they stop you or make you go, I don't know, but I don't think I'm on water tablets [P9]*

In terms of doses and the times of administration, again, most participants were confident in describing their medication regime. Doses were commonly described in terms of the number of tablets rather than their strength:

*I take four altogether in the morning, another one at lunchtime and then the same again at teatime, then my night-time one [P1]*

Changing tablets or brand names seemed to impact on knowledge confidence:

*I know what each one is supposed to do really. Well, one or two I'm not absolutely certain about. They've changed my tablets so much in the last three or four months that some that I was taking, I'm now not taking [P3]*

*You go to get them from the doctor or chemist and they're in different boxes each time and they're different colours. When you've taken some tablets for so many years one colour and you go back and they're another colour it's confusing. I think they buy them cheaper, don't they? [P5]*

In summary, most patients were reasonably confident about their knowledge of their medication, although threats to this knowledge, through changes to the regime were also described. The accuracy of knowledge about the use of medication has been studied, especially in relation to medication adherence (George and Shalansky, 2007; Van der Wal and Jaarsma, 2007; Riegel and Carlson, 2002), but no studies have been found which address individual confidence in understanding the actions of and use of heart failure medication. However, it is acknowledged that the accuracy of knowledge might be expected to relate to knowledge confidence.

## **SOCIAL INFLUENCES ON MEDICATION USE**

The belief that family or friends influenced medication use through practical assistance with medication management was described:

*My wife gives them to me in a container with each meal and when I go to bed, she gives them to me and says, 'here you are, take that' [P5]*

*My daughter-in-law bought me this thing with seven or eight drawers in it, one for each day of the week [P3]*

However, confidence in medication knowledge was poor when others took responsibility for medication management:

*My wife could tell you all about the tablets I'm on, because, I don't take much notice of that. My wife does it [P5]*

*I have to admit I've switched my brain off to a lot of it; my wife deals with most of that, fortunately. God knows how people deal with it when they're on their own [P7]*

*The nurse says to my wife, 'take him off this, put him on half of that, do this, do that' and between them they sort me out [P7]*

Gender differences were observed in that assistance with medication management was exclusively described by men in this sample. Men in partnerships tended to describe their wife managing their medication whilst women in partnerships did not describe any assistance with medication. However, this could be related to advancing age as women in partnerships, in this sample, tended to be younger.

The beliefs and advice of friends was noted to be a potential, negative influence on the use of medication:

*It's been suggested by friends of mine to reduce the dose and see what effect it has on me but I haven't tried [P12]*

*None of my family take as many tablets, none of my brothers and sisters have any, and then sometimes my friend says to me, 'why do you take so many tablets?' [P10]*

Social influences on the development of illness and treatment beliefs have been described by Horne et al (1999) and Leventhal et al (1997). Here, social influences seemed to have a largely positive effect on medication use through practical support, which may be related to gender. This influence is consistent with the findings of Stromberg et al (1999), who described the important role a spouse played in medication management by giving their partners their tablets at prescribed times. Wu et al (2007) also found that family members assisted with medication use by filling Dosette® Boxes. However, knowledge about medication may be negatively affected when medication is managed by others. A further finding is that beliefs about medication and potentially, adherence may be influenced by the beliefs and suggestions of others.

## **IMPACT OF MEDICATION USE ON LIFESTYLE**

The use of heart failure medication was described as interfering with aspects of lifestyle. Although, conceptually, this may be related to concerns about medication it seemed to

describe the more practical consequences of taking medication such as diuretics, and the time and effort involved in taking medication regularly and monitoring its effects:

*I am on water tablets but once you're getting rid of it, you go to the toilet every half hour or something like that, which is difficult when you are out [P3]*

*I don't sleep well. I'm up and down to the toilet what seems like half the night, that's the tablets [P6]*

*Having to take tablets all the time is a real nuisance [P2]*

*We used to visit my son in Herefordshire, but I don't drive there now. It's not so much the driving it's that I always seem to have an appointment with the nurse or doctor to check the effects of the tablets [P1]*

The unwanted effects of drug actions, particularly diuretics are well documented in heart failure (Nicholson, 2007; Cowie et al, 1999). The view that the management of a long-term condition involves substantial work effort by the individual is also supported here (Glaser and Strauss, 1967; DH, 2006b).

Overall, in addition to beliefs about the necessity of and concerns about medication, perceived knowledge about medication, social influences on medication use and the impact of medication use on lifestyle were also described. A strong, prevalent belief in the necessity of medication was found which seemed to be related to the belief that symptoms improved as a result of taking medication. However, concerns, particularly in relation to drug interactions and side-effects, especially at higher doses, were also prevalent as described in other studies (Riegel and Carlson, 2002; Stromberg et al, 1999). Concerns were enhanced by reading the patient information leaflets in the medication boxes.

Knowledge about medication was perceived to be high which was enhanced by reading the patient information leaflets. However, changes to the medication regime seemed to have a negative impact on perceived knowledge, similarly, when family members took responsibility for medication management, knowledge of medication seemed to be reduced. Medication use was believed to be influenced by friends and family with wives, in particular playing an important role in practical medication management through filling Dosette® Boxes and administering tablets. However, the beliefs of friends were found to have a potentially negative effect on medication use. The impact of heart failure medication on lifestyle, which can be considered a specific, practical medication concern,

was identified as a potential barrier to adherence as frequent diuresis and the time and effort involved in taking regular medication and monitoring its effects were highlighted.

In relation to the extended CSM (Horne et al, 1999), the existence of treatment representations of necessity and concern beliefs were supported in this study. That individuals viewed the use of medication as a balance between necessity and concerns was also supported. Social influences on medication use and the impact of medication use on lifestyle were themes developed inductively from the data, which although documented in the literature, have previously not been considered within the construct of treatment beliefs. Perceived confidence in medication knowledge, which may be related to the accuracy of knowledge, was also described in this sample and appears to be an original finding in relation to treatment beliefs.

#### **4.2.4 Self-care**

Self-care in heart failure has been conceptualised as consisting of self-care maintenance and self-care management behaviours (Dickson et al, 2006). Self-care maintenance includes adherence to recommended lifestyle behaviours and medication adherence. Self-care management strategies include symptom recognition, monitoring and management and the actions taken in response to those symptoms, such as seeking help.

### **ADHERENCE TO RECOMMENDED LIFESTYLE BEHAVIOURS**

In this sample, the following changes to lifestyle were described:

Reducing alcohol consumption:

*I've cut the drinking down. I used to have a regular sort of drink of an evening, gin and tonic or maybe a scotch but I don't do that anymore. I've certainly stopped the regular habit of drinking every evening [P12]*

*I've never drunk a lot but I used to have a glass of wine or so at the weekends. I don't drink now, I'll probably have one glass of wine Christmas day just with my dinner but other than that I don't drink [P8]*

The importance of eating a low fat diet:

*We have skimmed milk or semi-skimmed milk now and we also have Bertolli which is olive oil [P1]*

Avoiding caffeine was reported:

*I have cut out all caffeinated drinks [P12]*

*We have decaffeinated tea and coffee now [P2]*

One participant described her efforts to reduce smoking:

*I'm doing very well because since Christmas I have had four cigarettes a day, roll-ups, the fine, fine ones. I managed to stay four days without cigarettes [P10]*

Weight loss was mentioned:

*I've lost over a stone. If I was a bit stronger and lost another stone in weight that would do me good, which I'll try and do [P12]*

Exercise was seen as important in a physical sense and also as a social activity:

*I know exercise is important and what I've been doing is walking as fast as I can and I can feel my heart going but it's normal, it's like it used to, like when you run, it beats a bit faster and it's a good feeling [P11]*

*I go to town on Monday mornings. It gives me a chance to walk around and so I suppose that in the process of doing that I probably do a half a mile or something and I enjoy seeing people, getting out and about [P1]*

Changes in lifestyle were also influenced by other illnesses:

*You should exercise regularly if you can but you can only do what you can do and I can't exercise. I can't take things with sugar because of my diabetes. I've got a hiatus hernia which if I eat fat gives me a painful stomach and also I've got gallstones which if I eat fatty foods are very painful [P5]*

These behaviours are consistent with recommended self-care behaviour in heart failure (Riegel et al, 2009a; Dickson et al, 2006; Jaarsma et al 2000b). However, other behaviours such as limiting salt (sodium) intake and restricting fluids were not generally described with only one participant mentioning a reduction in their salt intake and no participants reportedly restricting their fluid intake. This finding is in contrast to a review of studies by Van de Wal and Jaarsma et al (2007) where adherence to a low sodium diet ranged from 13% to 75% and to a fluid restriction from 23% to 70%.

Lifestyle changes, such as taking a low fat diet, were not specifically discussed in relation to controlling heart failure but rather seemed to be described as part of an overall 'healthy lifestyle' or in response to co-morbidities. That spouses were also described as making dietary changes seems to support the lack of specificity of this behaviour to heart failure. Those behaviours which might be considered most specific to heart failure, namely reducing salt and fluid intake were infrequently described, suggesting a lack of understanding of the purpose of these lifestyle changes in relation to the illness.

## **ADHERENCE TO MEDICATION**

Adherence to medication was reportedly high with many participants describing full adherence:

*I never miss doses I'm very, very vigilant [P7]*

*I'm on lots of tablets and I take them without fail. I don't forget [P9]*

Strategies to maintain adherence such as Dosette® Boxes and other *aide memoir* were frequently described, particularly when forgetfulness was also apparent:

*I take them altogether in the morning. I've got a little pillbox because I'd just forget. sometimes they all look the same, especially when you're half asleep so they're all set out and then I know. Sometimes like today, I nearly forgot to take them and if I hadn't had that pillbox, especially with my memory, I would have stood there and thought 'have I taken them?' Whereas, I just went over and thought, 'Oh no, I haven't taken them' [P8]*

*I fill the things up every morning, and the water tablets, if I don't take one in the morning because I'm going out, I lay the mop on the floor to remind me so that when I come home I take one as soon as I get in, so I've got my own system for doing it [P11]*

At times, incomplete adherence was unintentional through forgetfulness or due to the complexity of the treatment regime:

*I sometimes forget to take one of them, my night-time beta blocker [P8]*

*Sometimes when I come to take them in the mornings, if there's one tablet missing, I haven't a clue which one. I try to compare them to the next day and sometimes I find it, and sometimes I don't [P3]*

*When you go to hospital they've got a tendency to take you off all your tablets and change them all; I don't know why that is. That completely destroys my routine for about a month or two and I have trouble getting them right [P1]*

Intentional non-adherence was described by two participants through adjusting doses to avoid side-effects or omitting specific tablets:

*Aspirin gives me a terrible stomach ache so I just take a quarter of one [P10]*

This same participant described omitting specific tablets as a way of dealing with a negative emotional response to the illness:

*When you take medications it is because you are not well and when you are not well you don't like it. The tablets always remind you that you are ill so it makes me feel better not taking so many, so I try to skip some of them. I will skip the lunchtime ones. One of them is three times a day; I just take one in the morning and in the night, not the lunchtime one. I skip the tablet for cholesterol, I think I will escape [P10]*

A second participant omitted specific tablets due to doubts about necessity:

*My cholesterol was coming down because of it (the tablet) and then it was holding steady at, I think it was 4.2 or something like that, so I thought, 'now I'm at a reasonable level, I'll come off, and if I go up I'll start on them again' [P2]*

*I'd like to stop all of them and see what happens and if necessary come back on them again. That to me would be a reasonable thing to request or expect. I'd like to come off the tablets, maybe one by one and see, with regular check-ups, if I need to go back on them again [P2]*

High levels of medication adherence, as reported in this sample are in line with those reported by Ekman et al (2006), Van de Wal et al (2004) and Granger et al (2005). Adherence was enhanced by the use of medication aids such as Dosette Boxes®. Threats to unintentional non-adherence were the symptom of forgetfulness, the complexity of the treatment regime, as indicated by a high number of tablets and administration times and frequent changes to the treatment regime. Forgetfulness, which may be related to cognitive deficits in heart failure, was also found to be related to non-adherence by Dickson et al (2007b). The complexity of the treatment regime has been



linked to medication non-adherence in studies by George and Shalansky (2007), Van der Wal and Jaarsma (2007) and Riegel and Carlson (2002).

In terms of beliefs, Ekman et al (2006) found that a strong belief that medication would improve symptoms was positively associated with medication adherence. Doubts about the necessity of medication seemed to be related to intentional non-adherence by one participant in this study. The presence of side-effects was also a barrier to adherence for one participant which may indicate a specific concern about medication. Intentional non-adherence was also described as a coping strategy to manage the negative emotional effects of the illness which seems to be an original finding, though one which is consistent with the CSM.

### **MONITORING SYMPTOMS AND THE EFFECTS OF MEDICATION**

Monitoring changes in symptoms requires that they are first recognised as symptoms of heart failure. As discussed in identity, differentiating heart failure symptoms from other illnesses, emotions and the effects of medication was difficult for some participants. An awareness of changing symptoms was however, described by a small number of participants:

*In the morning when you get up, usually you don't feel in the mood... you feel so tired that, 'here we go again!' You get tired, you sit, you are uncomfortable, you go to the settee, you're uncomfortable and... it starts like that. You're lying in bed, you can't breathe, so you get up...that's how the routine starts [P10]*

*I know when my blood pressure goes up and I know when it goes down. I notice pretty well straight away. It's just this funny head, really, that's the signal [P7]*

Monitoring of blood pressure was carried out by this participant's wife:

*Every day my wife does it; she's my personal nurse! She checks my blood pressure in the morning and then if I'm.....whoa....during the day, she'll check it again [P7]*

However, most commonly monitoring the condition was seen as the responsibility of the HFN or GP:

*The nurse calls on a regular basis and I see a doctor. He has a clinic every month, usually I see him once every three months. They check you over, make sure you're OK [P1]*

*The cardiac nurse calls on me once a month to take my blood pressure and things like that [P2]*

Monitoring by health professionals was also to check for the negative effects of medication:

*Every three months I have a blood test to check the liver and the kidneys [P10]*

*I have to have my kidneys checked because one of the tablets I'm on can affect your kidneys [P8]*

Overall, most participants were unable to recognise changing or deteriorating symptoms. Monitoring the condition and the effects of medication was seen as the responsibility of health professionals, sometimes assisted by a spouse. Active self-monitoring of symptoms such as ankle oedema and assessing fluid status through daily or regular weighing were not reported in this sample. Daily or regular weighing was found to be carried out by 52% of patients in a study by Van de Wal et al (2004) and ranged from 14% to 79% in a review of the literature by Van de Wal and Jaarsma (2007). In this sample, as oedema was not a reported symptom of the illness, assessment of fluid status through regular weighing perhaps explains the absence of this monitoring behaviour.

## **MANAGING SYMPTOMS**

The management of symptoms was largely passive in that resting was most frequently described:

*If I get this funny head, I have to go to sit down or lie down. I go and sit down and after three, four or five minutes, it clears [P3]*

*When my breath gets short I deliberately stand still or sit down and expel all the air out of my lungs so that I've got to take a deep breath and then that makes me breathe in and out and I can do that for five minutes and sort of come back to normal [P1]*

Related to the suggestion that rest was seen as a remedy for symptoms, avoidance of lifting or straining as provoking factors was described:

*I've got to be very careful what I do. Not strain for everything [P3]*

*Anything heavy, I don't lift [P9]*

As with medication management, the protective influence of female family members was described:

*She won't let me lift anything heavy. I'd have a go at anything really but she won't let me do it. She won't let me lift anything [P4]*

The ability to manage symptoms was described as a learning process gained by experience. These participants had heart failure for three and five years respectively:

*I'm learning to control it now. Yes, I'm learning [P10]*

*You learn, after a time, how to help yourself, I think [P1]*

In summary, symptoms were managed by resting and those behaviours thought to provoke symptoms, namely lifting and straining, were avoided. This was often 'enforced' by spouses. Managing symptoms was seen as learning process, implying that experience of the illness is important for this aspect of self-care. Level of experience or time since diagnosis was found to be an important factor in determining self-care ability by Carlson et al (2001) through an enhanced ability to recognise changing symptoms and the use of tried and tested management strategies.

## **MANAGING THE EMOTIONAL AND SOCIAL EFFECTS OF THE ILLNESS**

Managing the negative emotional and social effects of the illness was a theme developed inductively from this analysis. The following behaviours are not recognised in existing heart failure self-care checklists such as the EHFSBS or the SCHFI, but are consistent with the DH definition of self-care of '*dealing with the emotional changes...and maintaining those things that are important – work, socialising, family*' (DH, 2006a, p.2). Managing the emotional response to the illness is also explicit in the CSM.

Managing depression through activity and making an effort to maintain a positive attitude was described:

*I say to myself, 'it's no use being miserable, there's nobody to help you' and I take my bike and I ride around the block, around the park and come back and I feel better [P6]*

*You've got to say to yourself, 'get up off your backside and do something about it rather than sit there and feel sorry for yourself' [P12]*

Others described strategies to manage anxiety:

*I say to my husband, 'Right just talk to me for a minute, so I can pass it'. If my brain's thinking of something else I won't think of me panicking [P8]*

*I read, I watch TV. It relaxes me, keeps my mind occupied [P10]*

Making an effort to go out was reported as a means of managing emotions and maintaining social networks:

*We've started to go out to eat because we were just stuck here within the four walls all the time, which is great because it rallies you because you have to see people and speak to them [P12]*

*I make an effort to be sociable. My friend just rung and said, 'Would you like to come to the meeting this afternoon?' I said, 'Yes, I would'. It's not my church but they're very friendly. You're an hour or two out of the house and you meet people. I make an effort to get out [P6]*

One participant saw support groups as useful in terms of making social contacts:

*I belong to a scheme called the Rhythm of Life. It's just that people like this all get together. I've only been once and met a man that had it done (insertion of an internal cardioverter defibrillator, ICD) and I'd like to meet more people. I'm thinking about going back to some exercises where they sit down all the time. It might get me out a bit more. It's only once a week but you meet people and then you go out with them during the week so I have them here or go to their places [P11]*

The ability to go out was facilitated or hindered by the level of social support:

*I suddenly get the urge to see a bit of sky and sea and so my son took me down to the coast just so I could see a horizon, it was lovely [P1]*

*If I had someone to come out with me it might help, the right person, somebody that didn't panic, it would make it easier [P11]*

Making an effort to go out was most prevalent in those living alone who, in this sample, were women.

In summary, maintaining a positive attitude through keeping active, managing emotions such as anxiety and making a deliberate effort to go out were described. Qualitative studies such as Zambroski (2003) and Mahoney (2001) have also identified these behaviours in describing the experience of patients with heart failure. These behaviours could be described as actions to maintain HRQoL (Dunderdale et al, 2008). However, they could also be categorised as self-care behaviours according to the DH definition.

## **REPORTING AND SEEKING HELP**

Reporting symptoms and seeking help were described in urgent and non-urgent situations. In many cases, seeking emergency help was prompted by the presence of severe symptoms, particularly breathing difficulties:

*I can't control the breathing. That's when I have to call up and ask for assistance so I'll land up in hospital [P1]*

*I couldn't breathe, I rang the surgery and they said 'we'll get an ambulance straight away for you', because I didn't know what to do. I'm suffocating. I've been in three or four times like that [P11]*

Seeking help and reassurance from a GP or HFN was also described:

*I'll get a bit of a tummy ache or something like that. I just feel generally lethargic and down and I don't feel right so I'll go along and see the doctor and half the time it's just you want someone who knows what they're talking about to give you a word of advice [P1]*

*I can pick the phone up and she (the HFN) can give me an answer. You know, if there's always somebody at the end of the phone then you shouldn't have to worry about anything should you? [P12]*

For participants who experienced panic attacks a counsellor was important in managing the emotional response to the illness:

*She helped me a lot. She helped me understand what happened to me. She showed me how to deal with the panic attacks [P10]*

In summary, seeking help as an emergency with resultant hospital admission was reported in this sample which is consistent with the documented high admission rates in

heart failure (Petersen et al, 2002). This may be due to an inability to recognise and manage deteriorating symptoms as described by Horowitz et al (2004).

When the GP or HFN was contacted, this was primarily to seek advice or reassurance in response to worry or anxiety, a behaviour which can be viewed as a way of managing the emotional effects of the illness. That a counsellor was also an important resource for some, seems to support this.

In conclusion, adherence to a number of recommended lifestyle changes was described. Limiting alcohol intake, taking regular exercise, smoking reduction or cessation, making dietary changes such as eating a low fat diet and avoiding caffeine and losing weight were reported changes. These behaviours can be considered part of a 'healthy lifestyle' and relatively non-specific to heart failure. Behaviours such as adhering to a low sodium diet and restricting fluid intake, which can be considered most specific to heart failure (Dickson et al, 2006; Jaarsma et al 2000b), were mentioned infrequently or not at all. Adherence to heart failure medication was reportedly high with Dosette® boxes used to facilitate this. Incomplete adherence was also described through forgetfulness and the complexity of the treatment regime as found in studies by George and Shalansky (2007), Van der Wal and Jaarsma (2007) and Riegel and Carlson (2002). Intentional non-adherence appeared to be a coping mechanism for anxiety or due to weak beliefs about the necessity of medication or concerns about side-effects, in some participants.

Although deteriorating symptoms were recognised by some, monitoring the illness and the effects of medication were seen as the responsibility of health professionals. The practice of regular weighing, an important aspect of self-care monitoring (Dickson et al, 2006; Jaarsma et al 2000b), was not evident in this sample. Managing symptoms was largely a passive process involving resting and avoiding activities perceived to provoke symptoms. Managing symptoms was also described as a learning process, gained through experience and so may be related to length of time living with the illness. As well as managing physical symptoms, managing negative emotions and the social consequences of the illness were described. This included maintaining a positive attitude, keeping active, managing emotions, such as anxiety, and making an effort to go out. This is consistent with the Department of Health (DH, 2006a) definition of self-care and the CSM, in that coping behaviours are directed at both symptoms and emotions.

In terms of reporting, seeking emergency help in response to deteriorating symptoms, especially breathlessness was evident, perhaps as a consequence of the inability to monitor and manage symptoms as described above and supported by Horowitz et al

(2004). Non-urgent help was sought from GPs, HFNs and a counsellor, largely to seek reassurance and manage the emotional effects of the illness.

In relation to the domains of self-care described by Dickson et al (2006), the existence of self-care maintenance behaviours including adherence to lifestyle factors and medication, were apparent from this data. Self-care management strategies including monitoring and managing symptoms, reporting and seeking help were also described in this sample. However, an additional theme of managing the emotional and social consequences of heart failure was also identified.

One purpose of the interview data was to test the use of the CSM as the theoretical framework. The following section draws together illness representations, treatment beliefs and self-care in a case study example which illustrates the 'fit' of this data to the CSM.

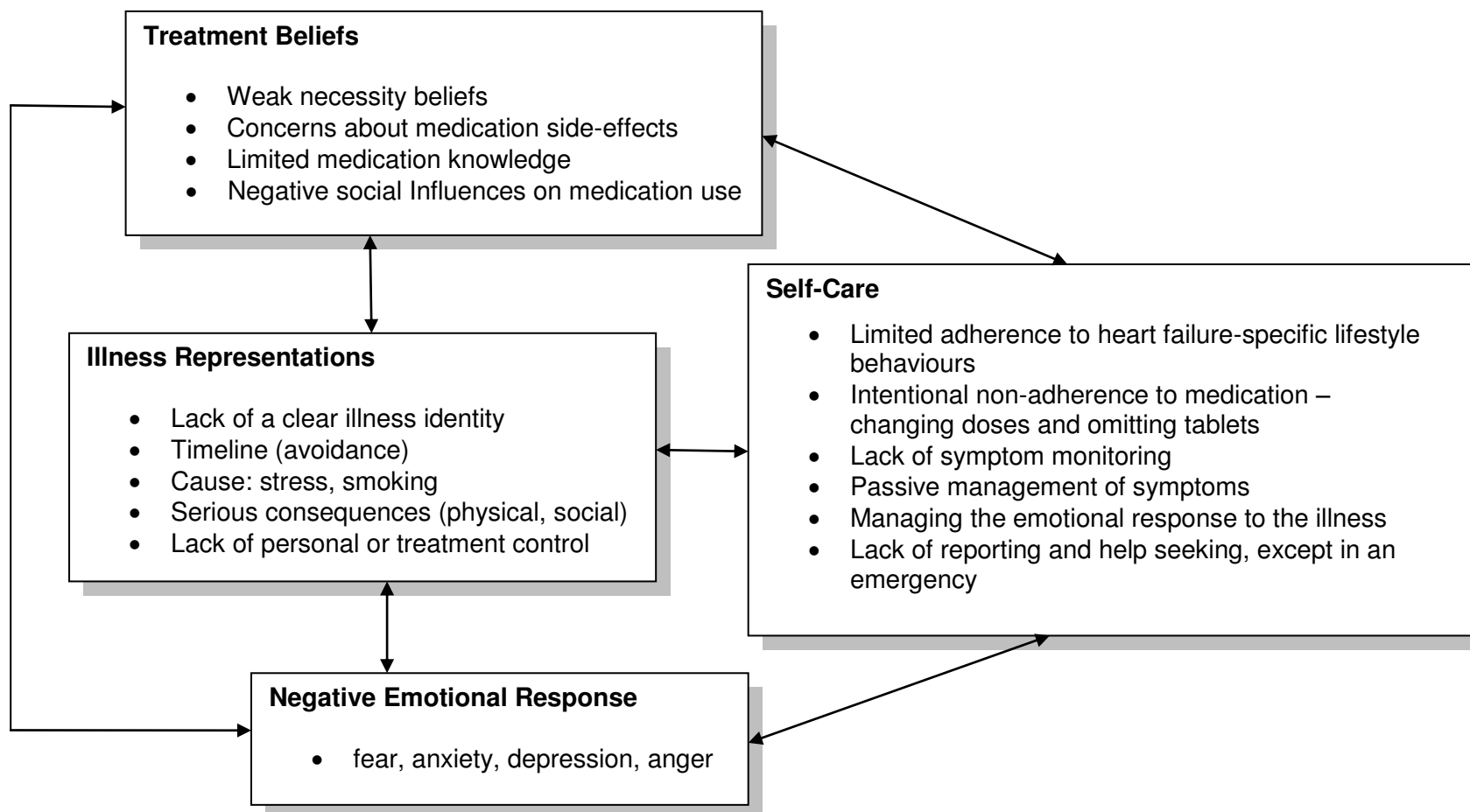
#### **4.2.5 Application of the CSM**

A case study of P10, a 59 year old woman, is presented in Figure 4.4. This participant was chosen as she demonstrated limited self-care and a complex system of beliefs.

Overall, there was a lack of a clear illness identity as she could not explain what was wrong with her heart and did not differentiate between symptoms of angina and heart failure. Although breathlessness was recognised as being due to the condition, it could not be differentiated from panic attacks. The illness was attributed primarily to family stress but smoking was also identified as a potential cause although its contribution to the development of the illness was perceived as limited. A total lack of control over the illness was described and there was a belief that the illness had serious consequences which were mainly physical, although a reduction in social activities was also reported. This participant described her illness as 'puzzling', demonstrating a lack of illness coherence. A strong, negative emotional response to the illness was apparent with anger, fear, anxiety and depression experienced. She was too fearful to think about the future, so beliefs about timeline were difficult to assess. There were doubts about the necessity of medication and concerns about side-effects. Confidence in her knowledge of the actions of medication was limited and the views of friends were important in determining her attitude to medication.

Figure 4.4

Case Study Illustration of the CSM





In terms of self-care maintenance behaviours, reducing but not stopping smoking was reported and as she believed she already eat a healthy diet, no further lifestyle changes had been made. This is consistent with the belief that the illness was not caused or controlled by lifestyle behaviours. Intentional non-adherence to medication was described in terms of reducing doses and skipping selected tablets due to concerns about medication side-effects, particularly those attributed to aspirin, and as a strategy to reduce the emotional impact of the illness, as taking medication was seen as a reminder of that she was ill. This behaviour is also consistent with the belief that stress was the main cause of the illness. The active monitoring of symptoms, through for example, regular weighing was not described, illustrating a lack of a clear illness identity as the purpose of regular weighing was not known. Symptoms such as breathlessness and tiredness were managed by resting and relaxing, which represents a coherent view of stress as the cause of the illness. Strategies aimed at managing negative emotions were described, namely, keeping occupied, trying not to think about the illness and by avoiding the use of medication. Help was sought only as an emergency when symptoms worsened, highlighting a lack of control over the illness.

#### **4.3 CONCLUSION**

In conclusion, the purpose of the qualitative data was to inform the adaptation or development of the questionnaires and to test the application of the CSM. In summary, while no new themes were identified from these data in terms of illness representations, a need was identified to make symptoms and causes specific to heart failure in the IPQ-R (Moss-Morris et al, 2002). Three additional domains of treatment beliefs were added to necessity and concern beliefs as described in the BMQ by Horne et al (1999). These were perceived knowledge about medication, social influences on medication use and the impact of medication use on lifestyle. In terms of self-care, the concepts of self-care maintenance and self-care management (Dickson et al, 2006) could be applied to these data with specific behaviours in heart failure identified. In addition, managing the emotional and social consequences of the illness was identified as an important aspect of self-care by participants and could be described as a coping strategy according to the CSM.

An extended CSM including treatment beliefs could, therefore, be usefully applied to this data. However, some difficulties were apparent. A lack of a clear illness identity meant some participants described other cardiac conditions along with heart failure so that, at times, it was difficult to isolate beliefs about different conditions. Depression could theoretically be categorised as an emotional response to the illness, a symptom of heart failure or a co-

morbidity. Here, it has been categorised as an emotional response as this was the context in which the participants described it and consistent with the CSM. Illness coherence could be defined not only as the belief that the illness makes sense but also in terms of the ability to demonstrate this through the consistency between other illness representations and few misconceptions. This is discussed further in Chapter seven.

## **CHAPTER FIVE: THE ADAPTATION AND DEVELOPMENT OF THE QUESTIONNAIRES AND THE PILOT STUDY**

In this chapter the adaptation of the questionnaires assessing illness representations, treatment beliefs and self-care is discussed. The development of a socio-demographic questionnaire is also described. This adaptation or development was based on the qualitative findings, published literature and the expert opinion of HFNs. The pilot study is then presented, the purpose of which was to test the recruitment, data collection and data analysis procedures to be used in the main survey (phase two). Further amendments to the questionnaires in the light of the pilot study and through discussion with a small number of heart failure patients, are finally described.

From the analysis of the interview data, discussed in the previous chapter, the IPQ-R was found to accurately describe the illness representations of heart failure patients, although there was a need to make the identity (symptoms) and causal sub-scales specific to heart failure. Beliefs about the necessary of medication and concerns about its use were themes in the BMQ and were also described by the heart failure patients. In addition, three new constructs were identified – perceived medication knowledge, social influences on medication use and the impact of medication use on lifestyle. Self-care was described by the heart failure patients in terms of adherence to lifestyle behaviours, adherence to medication, monitoring and managing symptoms and reporting and help-seeking behaviour, as defined in a model of self-care maintenance and self-care management strategies according to Dickson et al (2006). In addition, patients described the use of strategies to manage the emotional and social consequences of the illness, as articulated by the CSM and the DH definition of self-care (DH, 2006a).

### **5.1 THE INITIAL ADAPTATION AND DEVELOPMENT OF THE QUESTIONNAIRES**

The original, validated questionnaires (the IPQ-R, BMQ and EHFScBS) are given in Appendices 1-3. The adapted versions, as used in the pilot study, are each labelled 'Version 1 (Pilot)' and given in Appendices 14-16. Changes made from the original questionnaires have been tracked and highlighted. The pilot version of the questionnaire assessing socio-demographic characteristics is given in Appendix 17.

In adapting or developing the questionnaires, general principles of questionnaire design according to Oppenheim (2002) were followed. Font size was maximised to make the questionnaires as easy to read as possible without excessively increasing the number of pages which might be a barrier to completion. Attention was paid to layout to try to make the questionnaires visually appealing and to provide sufficient space for respondents to record their answers. Shading was used to highlight instructions and differentiate between the columns of the response grids. The Arial style was chosen as this was believed to be most easily readable. The 'texture' of the questionnaire was varied using both open and closed questions, as Oppenheim (2002) suggests responses may be better when different types of question are used. Attention was paid to the order of questions so that, generally, questions on a similar theme were grouped together. Questions were kept as short and simple as reasonably possible with a maximum word limit of twenty words (Oppenheim, 2002). Questions were phrased to try to avoid jargon, unfamiliar words, leading questions, ambiguity, multiple ideas and double-negatives. The option for the response 'other' was made available where relevant and the instructions for completing the questionnaires were made as clear as possible. Reversed questions and 'filler' questions were used in order to minimise acquiescence bias or the tendency to agree to all statements (Oppenheim, 2002) This was especially important in assessing self-care behaviour where respondents might be tempted to state that they carried out recommended behaviour in order to be seen as compliant and present themselves in a positive light, so-called social desirability bias. The following sections discuss, in detail, the initial adaptation or development of each of the four questionnaires.

#### **5.1.1 Initial adaptation of the IPQ-R**

Moss-Morris et al (2002), advocate that the IPQ-R should be adapted to make it illness specific. Permission to use the IPQ-R and amend it if necessary was gained from Professor John Weinman, author of the IPQ and the IPQ-R. This adapted questionnaire is hereafter referred to as the IPQ-R (heart failure) (HF) (Appendix 14).

The qualitative data indicated that a number of changes to the IPQ-R were needed, although no new themes were identified. In summary, the term '*illness*' was changed to '*heart failure*' throughout; the assessment of the identity and causal domains were made heart failure specific; a minor wording change was made to one statement assessing the emotional response to the illness and two additional timeline items were added. The New York Heart Association (NYHA) Functional Classification (NYHA, 1984) was added as a measure of illness severity. These changes are summarised in Table 5.1 and discussed below.

**Table 5.1**      **Summary of Changes to the IPQ-R**

<b>Change</b>		
The term “Illness” changed to “heart failure” throughout		
NYHA Functional Classification scale added		
<b>Domain</b>	<b>Deleted Items</b>	<b>Additional Items</b>
Identity (symptoms)	pain; stiff joints;	Weight gain; forgetfulness; chest pain; palpitations; loss of appetite, swollen ankles; sexual difficulties; daytime sleepiness; fatigue; light-headedness;  Open question
Timeline	None	“my heart failure will get worse in time”; “I expect my heart failure to stay the same in the future”
Cause	A germ or virus; pollution in the environment; my own behaviour; my mental attitude; my emotional state; accident or injury; my personality; altered immunity	an infection; being overweight; a previous heart attack; other heart problems; other illnesses; medical treatment for other illnesses; high blood pressure
Emotional Response	None	“my illness makes me feel angry or frustrated”

The first section of the IPQ-R addresses the illness representation of identity and consists of a list of symptoms. Respondents are asked firstly, whether these symptoms have been experienced and secondly, whether they are believed to be due to the identified illness. From the qualitative findings and the heart failure literature, those symptoms not commonly recognised as symptoms of heart failure were removed, for example, ‘*stiff joints*’. Commonly identified symptoms of heart failure, not already included, were added. These were: ‘*weight gain*’, ‘*forgetfulness*’, ‘*daytime sleepiness*’, ‘*loss of appetite*’, ‘*swollen ankles*’ and ‘*sexual difficulties*’. Symptoms more typical of other cardiac conditions - ‘*chest pain*’ and ‘*palpitations*’ - were also added as it was thought that this might determine the ability of respondents to differentiate the symptoms of heart failure from other cardiac conditions, as this had been problematic for some interviewees and described in the studies reviewed by Jeon (2010). Two other symptoms listed in the IPQ-R were amended in order to use the language of heart failure patients. The term ‘*tiredness*’ was added to ‘*fatigue*’ and ‘*light-headedness*’ was added to ‘*dizziness*’. Given the high number and diversity of heart failure symptoms, an open question was added for respondents to list any other symptoms that they believed were related to their heart failure.

The assessment of the causal domain was also adapted to be specific to heart failure. Like identity, those items not identified as potential causes by either the literature or the qualitative data were removed, for example, *'altered immunity'* and *'accident or injury'*. Items added were *'being overweight'*, *'a previous heart attack'*, *'other heart problems'*, *'medical treatment for other illness'* and *'high blood pressure'*. The item *'a germ or virus'* was changed to *'an infection'* to better reflect the terminology of heart failure patients and include bacterial infections, for example.

In the IPQ-R, the illness representations of timeline, consequences, cure/control, coherence and emotional response are assessed as separate domains or sub-scales using a 5-point Likert scale. The qualitative data and literature indicated that these statements were applicable to heart failure so only minimal changes were made. The statement *'my illness makes me feel angry'* was amended to *'my heart failure makes me feel angry or frustrated'* as frustration was frequently described by the interview participants and was considered to be related to anger. The IPQ-R includes a timeline item of *'my illness will improve in time'*. However, alternative statements in relation to the perceived future progression of the illness are not included. The interview data suggested that the statements of *'my heart failure will get worse in time'* and *'I expect my heart failure to stay the same in the future'* were recognisable to heart failure patients and so were added.

It has been suggested that the severity of the illness may influence illness beliefs and behaviour (Cameron and Moss-Morris, 2004). In heart failure, the severity of the illness has been found to influence self-care in studies by Wu et al (2007) and Rockwell and Riegel (2001). The 'gold standard' in determining illness severity in heart failure is the echocardiogram, which quantifies the ejection fraction or the effectiveness of the cardiac pump (NICE, 2010). Since ethical permission to access the patients' medical notes was not sought and the questionnaires were completed anonymously, this measure was not available. Therefore, a measure of functional ability was used rather than a direct measure of disease severity. The NYHA Functional Classification (NYHA, 1984), discussed in Chapter two, is a widely used self-report measure which asks patients to assess the perceived level of physical activity needed to provoke symptoms, primarily breathlessness (Wu et al, 2007). Functional ability is ranked by Roman Numerals I to IV where IV represents the most severe impairment. Although, functional ability can be considered an illness-related factor rather than a belief, its dependence on perceived symptoms meant that it seemed appropriate as part of the IPQ-R (HF).

### 5.1.2 Additions to the BMQ

Permission to adapt the BMQ was sought from the author, Professor Robert Horne. However, despite a number of attempts to contact him by e.mail and telephone, no response was received. In hindsight, other methods might have been tried, for example, a letter or a third-party introduction. Although published work by Horne et al (1999) suggest the BMQ can be adapted to make it illness and/or drug specific, without explicit permission, the decision was made to keep the BMQ intact but to make it heart failure specific by adding items and domains which could be analysed separately. This questionnaire is now referred to as the 'Medication Use in Heart Failure Questionnaire' or MUHFQ, which incorporates the BMQ (Appendix 15). A summary of these additions is given in Table 5.2.

Table 5.2      Summary of Additions to the BMQ

Domain	Additional items
Necessity	"my symptoms improve when I take my tablets"
Concerns	"I sometimes worry about the effect of taking lots of different tablets"
Medication Knowledge (New)	"I understand why I need specific tablets"; "I know when to take my tablets"; "I know the dose (strength) of my tablets"; "I am unsure whether I should take medicines that I buy myself, with the tablets prescribed for me"; "I know which symptoms are due to my heart failure and which are the effects of my tablets";
Social Influences on Medication use (New)	"my family or friends help me to take my tablets"; "I would find it difficult to take my tablets without help from my family or friends"; "I follow the advice of my family or friends about taking my tablets";
Impact of Medication Use on Lifestyle (New)	"taking my tablets is influenced by my religious beliefs"; "I find it difficult to take my tablets when I go out"

The MUHFQ assesses beliefs about the necessity of and concerns about medication (the BMQ), together with three additional domains of medication knowledge, social influences on medication use and the impact of medication use on lifestyle, as identified from the qualitative data. It was hypothesised that, along with necessity and concern beliefs, these factors may influence adherence to heart failure medication. Attitudinal statements were assessed on a 5-point Likert scale. The statement '*my symptoms improve when I take my tablets*' was added as a necessity item and '*I sometimes worry about the effect of taking lots of different tablets*' was added as a concern as these items were identified in the interview data but not addressed in the BMQ.

In developing the new domains, an item pool was generated since, according to Oppenheim (2002), there are inherent risks associated with assessing the complex phenomenon of attitudes in a single item. The medication knowledge domain consisted of five items which aimed to assess perceived knowledge of the purpose of the medication, the dosage and timing of medication, differentiating the effects of medication from the illness and the concurrent use of prescribed and over-the-counter (OTC) medication, as suggested by the qualitative data. Three items assessed the perceived influence of family members and friends in terms of their treatment beliefs and practical medication management. Finally, the impact of medication use on lifestyle was assessed in general terms and in relation to going out, also identified from the qualitative data. The impact of religious beliefs on medication use was also included as according to Sabate (2003), this may also influence adherence to medication.

### **5.1.3 Initial adaptation of the EHFS CBS**

Permission to adapt if necessary and use the European Heart Failure Self-Care Behaviour Scale (EHFS CBS) was gained from the author, Professor Tiny Jaarsma. However, since this questionnaire was developed in Sweden, it was recognised that the self-care behaviours identified may not be those recommended in a UK healthcare system, operating under different clinical guidelines and organisational structures. The reliability of the EHFS CBS in a UK population has also been questioned (Shuldham et al, 2007). The interview data and the DH definition of self-care (DH, 2006a) also suggest that self-care includes more than adherence behaviour, which is the focus of the EHFS CBS. Therefore, the decision was made to develop a self-care questionnaire using findings from the qualitative data, the literature (including the EHFS CBS) and behaviours identified by HFNs. The reason for using an expert group of HFNs in addition to the patient perspective was the belief that to be meaningful, self-care should include behaviours believed to improve clinical outcomes. For example, the self-care behaviour of restricting sodium intake is believed to prevent fluid overload and resulting exacerbation of symptoms (Nicholson, 2007). It was felt that in addition to published evidence, specialist HFNs were best placed to identify those behaviours.

A nominal group technique (NGT) was chosen as the method of collecting data from a group of thirteen specialist HFNs and one heart failure Nurse Consultant, representing four PCTs and one Acute NHS Hospital Trust in the locality. NGT is described as a group-based method of data collection which explores a specific question, in-depth, among a target population (Delbecg and Van de Ven, 1971). The purpose of the technique is to generate information in



response to a specific issue which can then be prioritised. By presenting results qualitatively and quantitatively, NGT is a mixed methods approach which is consistent with the philosophy of this research. A number of advantages are noted by Potter et al (2004). These include time-efficiency, cost-effectiveness and easy implementation through minimal pre-meeting preparation time. Time-efficiency was particularly important as the data were collected at a regional heart failure service meeting with only a limited amount of time allocated in the agenda. A further advantage was that most members of the group had had some experience of the process as it is a common method of evaluation used in nursing education, locally.

Potter et al (2004) describe a 5-step process for conducting a nominal group which was followed here. First, the purpose and procedures of the meeting were explained. The definition of self-care according to the DH (2006a) was given and the nurses were asked to identify specific, self-care behaviours in heart failure by individually generating items for a few minutes before sharing these ideas on a flipchart. When no new items were identified, a copy of the EHFSBS was presented and the nurses were asked to review their list of self-care behaviours in the light of this validated questionnaire, making any additions or deletions to their list. From this, only the EHFSBS item '*I get a flu and pneumonia vaccine*' was added. It was interesting to note that adherence to recommended advice and help-seeking behaviour were emphasised by the HFNs, suggesting these nurses held a predominantly biomedical model of self-care. The self-management of symptoms and behaviours aimed at promoting emotional and social well-being were important to the interviewees but not identified by the HFNs. The nurses were then asked to individually rate the items in terms of importance using a 7-point scale where 1 = 'not important' to 7 = 'very important', thus prioritising behaviours.

The findings were then collated and analysed using descriptive statistics. The mean score and standard deviation for each item was calculated and the items were ranked in order of importance (Table 5.3). All items were highly scored (mean score, 5.00 or above). Those items ranked most highly were weighing oneself regularly, monitoring changes, reporting changes and medication adherence. Those with the lowest rank were avoiding non-steroidal anti-inflammatory drugs (NSAIDs), consuming alcohol within government recommended limits, having flu and pneumonia vaccinations, following a healthy cardiac diet and taking appropriate exercise. On reflection, these items are either least specific to heart failure or most dependent on individual patient characteristics and hence, least universal.

Table 5.3 Nominal Group Technique (NGT) Results

	Item	E1	E2	E3	E4	E5	E6	E7	E8	E9	E10	E11	E12	E13	E14	Mean	SD (±)
1	Take appropriate exercise	3	4	5	5	6	5	4	7	6	6	4	4	6	5	5.00	1.21
2	Maintain level of activity	2	5	6	6	6	5	7	7	6	6	5	6	6	6	5.64	1.07
3	Weigh yourself regularly	7	7	7	7	7	6	7	6	7	6	5	7	7	7	6.64	1.21
4	Monitor changes in: sleep pattern; exercise tolerance; breathing (notice if you: have a cough; start waking at night; become more short of breath); fluid retention; have palpitations or falls; monitor effects of medications	7	7	7	7	7	7	7	7	7	7	7	7	7	7	7.00	1.21
5	Report changes in above; report chest pain;	6	7	7	7	7	7	7	6	7	7	6	7	7	7	6.78	0.43
6	Maintain fluid intake of 1.5-2l	6	7	7	6	5	6	7	6	6	6	4	6	6	5	5.92	0.80
7	Take a low salt diet	4	6	7	6	4	7	6	6	6	7	4	6	7	7	5.92	1.10
8	Follow a healthy cardiac diet	2	6	6	6	4	5	5	5	6	6	3	5	6	6	5.07	1.22
9	Take medications as prescribed; Alter medications as advised	3	7	7	7	7	7	6	7	7	6	6	7	7	7	6.50	1.05
10	Report side-effects of medication	6	7	7	7	3	5	6	6	6	7	6	6	7	6	6.07	1.03
11	Keep a current list of medications	2	6	5	5	5	7	7	5	7	7	6	5	7	5	5.64	1.34
12	Stop smoking	3	6	6	6	4	6	5	5	6	6	4	6	7	7	5.50	1.12
13	Avoid NSAIDs	3	6	4	6	4	6	4	6	6	6	4	5	5	5	5.00	1.00
14	Seek advice on OTC drugs	5	7	7	6	4	5	5	5	7	6	6	5	5	5	5.57	0.90
15	Seek help if unsure	5	7	7	7	3	6	7	7	7	7	7	5	7	7	6.35	1.17
16	Maintain drug refills	7	7	6	6	3	7	7	7	7	7	6	7	7	6	6.42	1.04
17	Drink alcohol within recommended limits	4	5	5	7	5	5	5	5	6	5	5	5	6	6	5.28	0.67
18	Have Flu and pneumonia vaccinations	3	6	6	5	4	5	6	5	6	5	5	6	6	6	5.28	0.88

KEY E= Expert Nurse Scores 1 = not important to 7 = very important

Using the nominal group data and the qualitative findings, the pilot version of the self-care questionnaire was developed. Items were worded as statements and assessed using a 5-point Likert scale. From the expert data, '*monitoring changes*' consisted of more than one element and was separated into monitoring changes in sleep patterns, exercise tolerance, and breathing, for example. Some items were merged. For example, '*avoiding NSAIDs*' and '*seeking advice on over-the-counter (OTC) drugs*' were merged into the single item '*If I need to take medicines which are not prescribed, I check with my pharmacist, doctor or nurse*'. From the qualitative data, the self-management item of resting when needed was added as this was commonly described in the interviews. Items addressing the management of the emotional and social consequences of the illness such as making an effort to go out and maintaining social networks, were also included.

The questionnaire, therefore, consisted of five domains: adherence to lifestyle advice, adherence to medication, monitoring changes, managing symptoms and the emotional and social consequences of the illness and reporting and seeking-help. These are broadly consistent with the concepts of self-care maintenance and self-care management behaviours according to Dickson et al (2006) and reflect self-care as defined by the DH (2006a).

A draft of the developed questionnaire was sent to the nurses who had participated in the nominal group, for comment. Three responded with one suggesting no changes. This low response may have been due to satisfaction with the questionnaire or a reluctance to engage further in its development, perhaps due to competing work demands. One comment received from two nurses was to omit the statement '*I eat a low fat diet*' as it was felt to be inappropriate for patients in the final stages of their illness with cachexia. The phrase '*vigorous exercise*', it was suggested, should be avoided as patients would be recommended to only exercise until they were '*slightly breathless but able to speak in sentences*'. Specifying the frequency of flu and pneumonia vaccinations was also thought to be necessary. The questionnaire was amended accordingly and resulted in Version 1 (Pilot) (Appendix 16).

Since the researcher and the local heart failure services, rather than the EHFSBS, drove the development of this questionnaire - and the pilot version was considerably different from the EHFSBS - it was decided that this was effectively a new questionnaire although acknowledging the use of the EHFSBS in its development. This questionnaire is now referred to as the, 'Looking After Yourself with Heart Failure Questionnaire' or LAYHFQ and was evaluated during the course of this work.

#### **5.1.4 Initial development of the Socio-Demographic Questionnaire (SDQ)**

A socio-demographic questionnaire (SDQ) was developed to describe the characteristics of the sample (Appendix 17). A secondary purpose was to be able to determine the influence of socio-demographic characteristics on self-care since Sabate (2003) describes socio-demographic and illness-related characteristics as related to adherence behaviour. From the literature, age, gender, economic status, ethnic origin, education level, the presence of co-morbidities, social support and the duration of the illness are suggested to be influencing factors on self-care in heart failure. In the SDQ, open questions assessed age, income, time since heart failure diagnosis and co-morbidities. Gender, ethnic origin as categorised according to the ONS (2008), social situation, educational qualifications and occupation required respondents to choose from a list of options.

### **5.2 THE PILOT STUDY**

A pilot study is described by Polit and Hungler (2001) as a small scale version or trial-run done in preparation for the main study. In addition to testing the adequacy of the procedures, these authors suggest that the principle focus of a pilot study is the assessment of the adequacy of the measurement instruments. In this section, the design of the pilot study and an overview of the procedures are given. As the procedures for sampling and recruitment, data collection, data analysis and ethical considerations remained the same for the main survey, these are discussed in detail, in Chapter six. The response rate and characteristics of the pilot sample are described before evaluating the study in terms of its overall aims. Changes made to the questionnaires in the light of the pilot analysis are discussed in section 5.3.

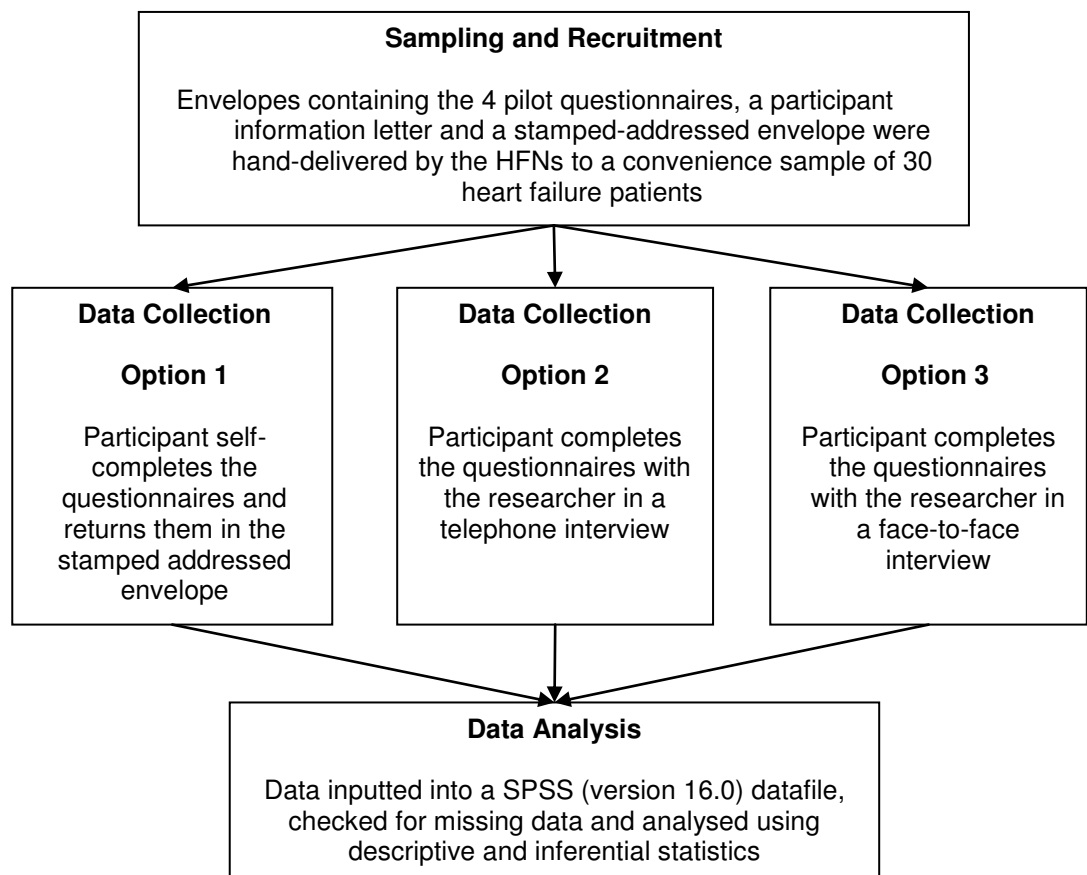
#### **5.2.1 Design and procedures**

The design of the pilot study and an overview of procedures are given in Figure 5.1. In terms of sampling and recruitment, each of the three heart failure services were asked to distribute ten envelopes (30 in total) to the first patients who met the inclusion and exclusion criteria as described for the qualitative phase in Chapter four, section 4.1.2. Therefore, the sample was one of convenience and hence not necessarily representative of the heart failure population. A response rate of one-third was estimated (De Vaus, 1996) so that a sample size of approximately ten participants would be used to test the procedures, gauge the likely response rate in the main survey, allow preliminary analysis and enable changes to be made to the questionnaires (Cormack et al, 2006). The sample was kept relatively small as those

participating would be excluded from taking part in the main survey as their responses may have been influenced by having previously completed the pilot questionnaires. Hence, too large a pilot sample would have reduced the number of available participants for the main survey.

The envelopes given out by the HFNs contained a participant information letter (Appendix 18), the pilot questionnaires (Appendices 14-17) and a stamped, addressed reply envelope. As in the qualitative study, the HFNs were briefed on the verbal information to be given to patients to minimise selection bias.

**Figure 5.1**     Pilot Study Design and Procedures



Participants were given three options by which to complete the questionnaires: to complete and return them by post in the pre-paid envelope (self-completion), to complete them in a telephone interview with the researcher or to complete them, in their own homes, in a face-to-face interview with the researcher. The purpose of offering these options was twofold; firstly, to try to maximise the response rate and secondly, in recognition of the characteristics of the

respondents since some participants were likely to be elderly or in poor health, for example, and may have found self-completion difficult given the length and complexity of the questionnaires.

A date of two weeks was given during which participants were requested to respond. This was considered a reasonable length of time in which to consider whether or not to participate, and to complete the questionnaires. If an interview was requested, participants were instructed to return the reply slip with their telephone number so that they could be contacted to arrange a convenient date and time for the interviews to be conducted.

In preparation for analysis, a datafile was set up in SPSS (version 16.0) according to the processes described by George and Mallery (2005). Each question was identified as a separate variable and labelled, for example, 'gender' and 'timeline'. The type of variable was then identified as either a numerical or string variable and defined as a nominal, ordinal or scale variable. This is discussed further in Chapter six.

### **5.2.2 Results**

In terms of recruitment, no difficulties were reported by the HFNs in delivering the envelopes, suggesting that the procedures were satisfactory. Twenty sets of questionnaires were returned, representing a response rate of two-thirds which was higher than anticipated (De Vaus, 2006). No participants selected the option of either the telephone or face-to-face interview as a means of completing the questionnaires, the consequences of which are discussed in section 5.4. This established that self-completion was achievable and the favoured method of completion. However, it was recognised that in a larger sample, some participants might still elect to complete the questionnaires in an interview.

Individual cases were coded and identified according to site and case number for example, B2 (Site B, Case 2,) and C4 (Site C, Case 4). Data from each case was then inputted into the datafile. The data were first scrutinised for missing responses which were then traced back to the individual questions for further reflection (discussed in section 5.3). The socio-demographic characteristics of the sample were descriptively analysed for means, ranges, standard deviations and frequencies. These results are presented in Table 5.4.

The mean age of the pilot sample was 68.6 years (range 31-89, SD  $\pm$  16.64). Average household income was £24,722 (range 8,500 – 60,000, SD $\pm$  17.00). The mean time with the

illness was 5.9 years (range 0.25-27.00, SD  $\pm$  7.70). 70% of the sample were men and 30% were women. 95% of participants described themselves as of White, British ethnic origin with 5% (n = 1) described as Asian, British. The majority of the sample (65%) lived with a partner or family with 35% living alone. Half the sample had no formal qualifications. Most (94.7%) were retired with 5.3% in paid employment. A high proportion (65%) reported having co-morbidities. According to the NYHA functional classification, most participants were classified as either class II or III, which describes moderate severity of heart failure.

**Table 5.4**      **Socio-Demographic Characteristics of the Pilot Sample**

	(n)	Range	Mean	SD ( $\pm$ )
Age	20	31-89	68.60	16.64
Household Income (£/yr)	5	8,500-60,000	24,722	17.00
Time since diagnosis (yrs)	20	0.25-27.00	5.90	7.7
	(n)	Frequency	%	
Gender	20			
Male		14	70.0	
Female		6	30.0	
Ethnic Origin	20			
White, British		19	95.0	
Asian, British		1	5.0	
Social Situation	20			
Lives alone		7	35.0	
Lives with partner/family		13	65.0	
Qualifications	18			
None formal		9	50.0	
GCSE/'O'Level or Equivalent		4	22.2	
'A' Level or Equivalent		2	11.1	
Degree		1	5.5	
Professional		2	11.1	
Occupation	19			
Employed		1	5.3	
Retired		18	94.7	
Co-morbidities	20			
Yes		13	65.0	
No		7	35.5	
NYHA	15			
Class I		1	6.7	
Class II		7	46.6	
Class III		6	40.0	
Class IV		1	6.7	

In order to test the feasibility of the data analysis methods, statistical tests which were to be used in the main survey were carried out. These results have not been reported in this thesis since their purpose was to test the feasibility of data analysis, rather than determine preliminary results. Internal consistency of the questionnaires was tested using Cronbach's alpha ( $\alpha$ ). Frequencies, means and standard deviations were used to describe the data and inferential statistics of chi-squared ( $X^2$ ), one way analysis of variance (ANOVA), Pearson's correlation co-efficient ( $r$ ) and multiple regression were carried out to determine relationships between variables. The use of these tests in relation to the main data is discussed in Chapter six.

### **5.3 FINAL DEVELOPMENT OF THE QUESTIONNAIRES**

The final development of the questionnaires was based on analysis of the pilot data and a process of member checking (Guba and Lincoln, 1995), the purpose of which was to enhance the validity of the questionnaires and to determine the ease with which the questionnaires could be completed.

All patients attending a clinic appointment with a HFN at Site A were approached and invited to participate in a one-to-one discussion on the use of the questionnaires. This clinic and site were chosen for convenience. Verbal consent was obtained following an explanation of the purpose of the research and what participation would involve. All patients attending the clinic agreed to participate. The sample consisted of three men and one woman. Participants were first asked to self-complete the questionnaires. One patient requested that the questionnaire was read out as he had poor vision. They were then asked the extent to which the instructions for completion were clear and to identify any questions which they found difficult to answer and for what reason. How the questions were being interpreted was also probed to make sure they were being answered in the way the researcher intended. All comments were noted and summarised (Appendix 19) and were considered in the final development of the questionnaires.

As a result of scrutinising the pilot questionnaires for missing data and following the member checks, a number of amendments were made to the pilot questionnaires. The final versions, as used in the main survey are given in Appendices 20-23 and labelled Version 2 (Final). Changes from the pilot versions have been tracked and highlighted. A discussion of the reliability and validity of the questionnaires is given in Chapter six.



### 5.3.1 Final amendments to the IPQ-R (HF)

The title of the questionnaire was changed to be more 'user-friendly', avoiding the use of complex acronyms which would not be relevant to the participant. The title '*Your Views About Your Heart Failure*' replaced the term IPQ-R (HF) for the purpose of data collection. On analysis of the pilot data it was noted that two items in the coherence domain of the IPQ-R had been inadvertently omitted in the development of the IPQ-R (HF) – '*my illness is a mystery to me*' and '*my illness doesn't make any sense to me*'. These were re-instated in the final version of the questionnaire.

Missing data in the pilot study were concentrated in three main areas: the identification of symptoms in the identity domain, the NYHA scale and the assessment of beliefs about causation. Analysis of the identity domain was problematic in that, while most participants were able to identify the symptoms they had experienced since having heart failure, most (n = 15, 75%) did not complete the second part of the question asking them to identify which of these symptoms were *related* to their heart failure. This may have been due to difficulty differentiating heart failure symptoms from other co-morbidities as suggested by the qualitative data. However, it was suggested by the clinic patients that they were not able to clearly differentiate between what was being asked in the first and second parts of the question. For the final version, the identity domain was simplified into a one-part question asking participants to identify those symptoms which they believed were due to their heart failure, as in the original IPQ (Weinman et al, 1996). The consequence of this was that the IPQ-R (HF) was not able to differentiate between beliefs about the symptoms of the illness and a general somatic effect, as described by Moss-Morris et al, (2002). From discussion with the clinic patients, one participant sought clarification for the term '*palpitations*' which was subsequently further defined as '*an awareness of my heart beating*'.

There was also some missing data for the NYHA scale (n = 5, 25%). Again, the reasons for this are speculative but on reflection, the instructions may not have been clear. This was confirmed by two clinic patients who said they were not sure what was being asked in this section. The use of the terms '*maximal and minimal exertion*' were also thought to be unclear and were subsequently reworded to give examples of levels of exertion, for example, '*I experience symptoms when I carry out any physical activity, for example, getting up from a chair*'. In addition, this scale may have been inadvertently missed out as it was a small section and presented as free-text. It was consequently presented as a grid, as other sections, in order to make it more visible. Respondents had been asked to circle their

response in a yes/no format which was unlike the rest of the questionnaire. It was therefore, put in the same 'tick-box' format as in other questions for ease of completion.

Missing data were also apparent in the assessment of beliefs about causation. Missing data were spread evenly with no one item consistently missed. It is suggested that those statements which were not relevant to an individual were simply skipped rather than answered '*disagree*' or '*disagree strongly*'. The instructions for completing this section were strengthened in the final version of the questionnaire by asking participants to respond to all statements.

Clinic patients found it necessary to read some questions a number of times in order to make sense of them. Lengthy, reversed questions in particular, required more careful reading which might have implications for the accuracy with which these questions were answered in the main survey. One participant commented that they found it more difficult to write 'free-form' in the open questions. As a result, open questions were kept to a minimum. The final version of the questionnaire is given in Appendix 20.

### **5.3.2 Final amendments to the MUHFQ**

On analysis of the pilot questionnaires, missing data were minimal. As in the IPQ-R (HF), the title was described in lay terms as '*Your views about your heart failure medication*' for the purpose of data collection. In relation to the domain of social influences on medication use, on reflection, an item assessing the influence of the views of others replaced a more general item so as to better reflect the findings of the qualitative study.

From discussion with the clinic patients, the statement relating to religious beliefs (part of the impact of medication use on lifestyle sub-scale) was not well understood with most participants seeking clarification of its meaning. This item was omitted in the final questionnaire as it was not based on either the qualitative findings or empirical research but on a general theory of adherence (Sabate, 2003) and so may not have been relevant in heart failure. A more general question assessing this domain - '*taking my tablets is part of my daily routine*' - replaced it. The final version of the MUHFQ is given in Appendix 21.

### **5.3.3 Final amendments to the LAYHFQ**

No consistently missing data were identified from the analysis of the pilot data. However, on reflection, five additional medication adherence items were added to the final version to better reflect the complexity and diversity of medication adherence behaviour, which it was felt, had

not been adequately addressed in the pilot questionnaire. For example, changing the dose or time of medication was added and non-adherence was differentiated into intentional and unintentional non-adherence by including an item on forgetting to take medication. In addition, questions assessing the uptake of flu and pneumonia vaccines were combined for simplicity.

The discussion with the clinic patients raised other issues. One patient sought a reminder of what was meant by alcohol units. A definition was, therefore, added in the final questionnaire. Three patients asked for clarification on the meaning of the term to 'check' for changes in symptoms. Following discussion with these patients and the clinic HFN, the term 'recognise' rather than 'check' was agreed upon and amended for the final questionnaire. The final version of this questionnaire is given in Appendix 22.

#### **5.3.4 Final amendments to the SDQ**

From the pilot study data only five respondents (25%) answered the question on income. From the discussion with the clinic patients, one participant commented that that they never answer questions about income. In gaining ethical approval, the NREC also commented that asking participants about income might negatively affect the response rate. This question was therefore, omitted in the final version of the questionnaire. As a result, neither the economic characteristics of the sample nor the economic influence on self-care could be assessed. This is discussed further in Chapter seven.

In response to a comment made by one clinic patient, the term '*wife/husband*' was included as an alternative to '*partner*' since this participant objected to the use of this term. One patient was unable to identify a point of diagnosis but was able to give an approximate length of time with the illness. Other patients also found this question difficult. As a result, the term '*length of time with heart failure*' replaced '*time since diagnosis*', in the final version of the questionnaire.

Oppenheim (2002) suggests that providing the participant with an explanation of the purpose of collecting socio-demographic data is beneficial in terms of response. An introductory statement was added to the questionnaire to facilitate this. On reflection, the question relating to co-morbidities was believed to be over-complicated and so was simplified to asking participants to just list any other illnesses. The opportunity to state '*equivalent*' qualifications was also added. This final version of the SDQ is given in Appendix 23.

## 5.4 CONCLUSION

In summary, this chapter has discussed the initial adaptation or development of questionnaires assessing illness representations - the IPQ-R (HF), treatment beliefs - the MUHFQ, self-care - the LAYHFQ and socio-demographic characteristics - the SDQ. The pilot study has been described which tested the procedures of sampling and recruitment, data collection and analysis. The final amendments to the questionnaires, based on missing pilot data and member checks, have also been discussed.

Creswell and Plano Clark (2007) describe the difficulty in making decisions about what findings to use in the development of questionnaires in a mixed method, exploratory, instrument development model. Here, the adaptation of the IPQ-R (HF) was relatively straightforward in that minimal changes were required from the IPQ-R, largely consisting of adding specific symptoms and causes of heart failure. Since the SDQ mostly consisted of closed, factual questions based on published literature, this too was relatively straightforward. In relation to the MUHFQ and the LAYHFQ, the main themes identified in the interview data were used to establish the additional domains of medication knowledge, the impact of medication use on lifestyle, social influences on medication use and the management of emotional and social effects of the illness. The nature of the items within these domains required critical appraisal of the relative strength of the evidence in order to justify the inclusion of items. That is, the qualitative findings, published literature and, in the case of the LAYHFQ, expert group opinion were used to make judgments about what was important and needed to be included in the questionnaires. A NGT was an effective method of gaining the views of an expert group of HFNs in a short time and achieved its aim of identifying self-care behaviours from a health professional perspective. Although the generalisability of the findings was not a major consideration in the pilot study, the decision to use a convenience sampling strategy had implications for the generalisability of the findings in the main survey, discussed in Chapter 6. In relation to recruitment, no difficulties were encountered by the HFNs in delivering the envelopes and a good response rate was achieved, suggesting that the recruitment procedures were satisfactory.

No participants in the pilot study chose to complete the questionnaires in a telephone or face-to-face interview; however, face-to-face interviews were carried out with clinic patients. This meant that the telephone interview method of data collection was untested which may have implications for the quality of some data in the main survey (discussed further in Chapter

seven). Setting up the datafile and the use of selected statistical tests suggested that the data analysis procedures were feasible in relation to the aims of the study.

In the final development of the questionnaires, analysis of the pilot data enabled missing data to be identified so that the questions to which this data referred could be scrutinised and the questions revised or omitted. In addition, the completion of the questionnaires with heart failure clinic patients was worthwhile in that some ambiguities and difficulties with completion were highlighted and corrected. However, on reflection, these member checks might have been carried out before the collection of the pilot data so that the pilot questionnaires might then have been more similar to the questionnaires used in the main survey. With hindsight, it may have been beneficial to carry out a second pilot study, using the final versions of the questionnaires. However, this in itself may have led to further changes and would have further reduced the population available for the main survey.

Overall, the pilot study was generally effective in achieving the aim of testing the procedures to be used in the main survey and enabling the final development of the questionnaires (Polit and Hungler, 2001). The final versions of the questionnaires were used to collect the data in phase two, the quantitative phase of the research which is discussed in the next chapter.

## **CHAPTER SIX: THE QUANTITATIVE PHASE - METHODS AND RESULTS**

This section discusses the methods and results of phase two, the main survey. An overview of the procedures is given followed by a discussion of sampling and recruitment, data collection methods, ethical considerations and data analysis. The internal consistency and construct validity of the questionnaires is then considered. In the results, the response rate is discussed and the socio-demographic and illness-related characteristics of the sample are presented. Illness representations, treatment beliefs and self-care are described before, presenting the relationships between these variables, according to the main aim of the research.

### **6.1 METHODS**

The procedures were as described for the pilot study in Chapter five, Figure 5.1. In summary, the three heart failure services were asked to distribute, by hand, envelopes containing a participant information letter (Appendix 18), the questionnaires (Appendices 20-23) and a stamped, addressed reply envelope to patients who met the inclusion and exclusion criteria as described for the qualitative phase (Chapter four). Participants were given three options by which to complete the questionnaires: to self-complete and return them by post in a pre-paid envelope or to complete them in either a face-to-face or telephone interview. If an interview was requested, participants were instructed to return the reply slip with their telephone number so that they could be contacted to arrange a convenient time. A date of two weeks was given by which participants were requested to respond. Structured interviews were carried out either face-to-face in the participants homes or over the telephone, as requested by participants.

An SPSS (Version 16.0) data file was set up, based on that used in the pilot study, so that each question represented a single variable. Cases were labelled according to site, case number and method of data collection. For example, Site A, Case 11, face-to-face interview was identified as A11F. Data were inputted and analysed using descriptive and inferential statistics. The following sections discuss sampling and recruitment, data collection methods, ethical considerations and data analysis.

#### **6.1.1 Sampling and recruitment**

Personal introduction by the HFNs was considered to be the most effective method of recruitment and was successful in the pilot study. This was especially important given the

lack of the initial response in the qualitative phase when invitations were posted. Oppenheim (2002) agrees that personal contact by an 'official' yields a higher response rate. This decision, however, had implications for the sampling strategy as the number of potential participants was now significantly reduced since, although the HFNs had a large number of patients registered to their service (in excess of 900 patients across the three sites), many were not in face-to-face contact with the HFNs through home or clinic visits. This significantly reduced the available population by approximately half so that a probability sample was not feasible based on the required sample size (discussed below). Therefore, a non-probability, convenience sampling strategy was used.

Polit and Hungler (2001) describe a convenience sample as the selection of the most readily available subjects. However, it is considered a weak form of sampling in that the sample may not be representative of the population. Patients visited by the HFNs or seen in clinic may have been more likely to be newly diagnosed, in poorer health or required more complicated management, for example. However, all heart failure patients were reviewed annually so patients likely to be more typical of the heart failure population would also be included. The characteristics of the sample are described in section 6.4.2.

Sample size was determined according to a Cohen's *d* power calculation based on the number of cases needed to produce statistically significant results in multiple regression. Potentially up to twenty predictor variables were identified – namely, all socio-demographic characteristics, illness representations and treatment beliefs. If all were included in the regression, to produce a statistical power of 0.8, with a medium effect size of 0.15 and a significance level of  $p = 0.05$ , a sample size of 156 would be needed ([www.statsdirect.com](http://www.statsdirect.com)).

Although Oppenheim (2002) suggests that a response rate of one-third or less is realistic for self-completed questionnaires, the pilot study suggested that a response rate significantly in excess of this was likely (66%). However, the number of questionnaires distributed in the main survey was based on this published estimate to try and ensure an adequate response. Therefore, it was calculated that 468 envelopes would need to be distributed to achieve a target sample size of 156. Essentially, this meant that the sample was equivalent to the total available population.

Sites A, B and C were unequal in terms of staffing levels. Sites A and C had a team of six HFNs with administrative support. Site B had only three nurses without administrative support. For this reason, the questionnaires were not distributed evenly across the three sites

but according to workload, as requested by the teams. The period of data collection was three months which, following discussion with the HFNs, was thought to be a sufficient length of time to distribute the questionnaires. Site A estimated that they could distribute 150 sets of questionnaires in this period, Site B, 90 and Site C, 180. This gave a total of 420 envelopes. Following this, further questionnaires could be distributed, if necessary, as new patients were registered to the service. The HFNs were asked to keep a record of those patients who had received the questionnaires so that reminder letters could be sent in the event of the target sample size not being achieved.

The HFNs were carefully briefed about the information that was to be verbally given to patients so that any bias in terms of recruitment was minimised. Oppenheim (2002) describes the necessity of giving consistent information where personal introductions are made so that individuals have equal information on which to decide whether or not to participate. The HFNs were instructed to briefly state the purpose of the research, what participation would involve, to emphasise that involvement was voluntary and to instruct patients to contact the researcher with any queries.

#### **6.1.2 Data collection**

Self-completion of the questionnaires was the anticipated, primary method of data collection based on the findings of the pilot study. In addition, a structured interview was used to collect data from those participants selecting either face-to-face or telephone interviews. The purpose of this standardised approach was to ensure responses were as consistent as possible between individuals and the different methods of data collection. This comparability of response is considered by Polit and Hungler (2001) to be one of the main advantages of structured interviews.

For the interviews, following introductions, the purpose of the research was explained as in the participant information letter and the opportunity was given to ask questions. The approximate length of time needed to complete the questionnaires was stated so that participants were able to allow sufficient time. In completing the questionnaires, the instructions and statements were read out exactly as written on the questionnaires and responses were recorded by the researcher. Clarification of the instructions or questions was given where requested. In this way it was hoped that participants were not inadvertently directed to any specific response. In contrast to the data collected in phase one, where the objective was to explore patient narratives, an objective approach was sought in this second



phase in order to minimise researcher bias. However, it is recognised that the relationship between the researcher and participant can never be free of biographical or social influences and complete objectivity is unobtainable (Denzin and Lincoln, 2005; Oakley, 1993).

Field notes were written immediately following the interviews. Comments were mainly in relation to methodological issues (Miles and Huberman, 1994). For example, the ease with which questions were answered was noted and those questions which needed to be explained were identified. The purpose of this was so that any missing data in the self-completed questionnaires might perhaps, be explained.

### **6.1.3 Ethical considerations**

Ethical review of the final questionnaires and the revised sampling strategy was sought from the NREC prior to commencement of the survey. Approval was gained following some clarification of the procedures (Appendix 5). Informed consent, access to participation, anonymity and confidentiality, and the ethical principles of non-maleficence and beneficence are discussed in relation to this phase of the study.

Written information was given in the participant information letter (Appendix 18) with informed consent being assumed by return of the completed questionnaires, as recommended by the NREC ([www.nres.org.uk](http://www.nres.org.uk)). Where data were collected by interview, informed consent was verbally obtained. However, as in phase one and the pilot study, it could be argued that since participants were recruited directly by the HFNs, there may have been an element of wanting to please the nurse who was known to them.

In terms of equal access to participation, applying the exclusion criteria, as discussed in Chapter four, meant that those unable to read and write a sufficient level of English were excluded, thus potentially compromising equality of access based on ethnic origin or level of education.

Participants were informed that the questionnaires were anonymous and it would be impossible to be identified from them. There was, however, a potential for anonymity to be compromised in the interviews since personal information (name, address or telephone number) were known. Therefore, at the time of data collection, the questionnaires were labelled according to site, number and method of data collection only. On completion of the interview, personal information was separated from the questionnaires and destroyed. Although the researcher's supervisor was made aware of the names, addresses, date and

time of the scheduled face-to-face interviews in order to safeguard the researcher, this information was destroyed on completion of the interview. Confidentiality was assured by not passing on the data to any third party and using it only for the stated purpose of the research.

In terms of non-maleficence, the HFNs were asked to exclude patients who were, in their view, too ill to take part in the study. This minimised the potential for physical and psychological discomfort in those most vulnerable. Participants were also given the contact details of a named HFN should they have any worries or concerns as a result of taking part. The HFNs were instructed to only select individuals and neighbourhoods they themselves would be willing to visit to minimise the risks to the researcher, should interviews need to be carried out in the participants' homes. It was stated in writing that there was likely to be no direct benefit to the participant by taking part (beneficence).

#### **6.1.4 Data analysis**

Variables were either described numerically or, less commonly, using words (string variables). For example, open questions on the questionnaire asked participants to list co-morbidities. Numerical variables were differentiated into continuous or discrete (categorical) variables. Continuous variables were those which could be assigned any value. The variable of 'time with illness' was therefore defined as a continuous variable since values were given in years and months. Discrete variables were those which could only be assigned certain values, in this case whole numbers. In this sample, all other variables were defined as discrete variables, for example, gender and social situation. Age was also defined as a discrete variable as values were given as whole numbers (years). However, in large samples, as in this case, age may be considered a continuous variable for the purpose of analysis (Coolican, 2009).

Numerical variables were further categorised as scale, ordinal or nominal measures. Scale variables have intrinsic numerical meaning and allow traditional mathematical manipulation. Here, age and time with illness were categorised as scale variables, for example, an individual who has had heart failure for two years has had the illness twice as long as someone who has had heart failure for one year. Ordinal variables also have intrinsic order but the numerical value is relatively meaningless. For example, variables which were assessed by responses on the Likert scales from -2 = strongly disagree through to +2 = strongly agree were categorised as ordinal variables. Nominal variables have no intrinsic order and the numerical values are merely used as labels, for example, gender, where 1 = male and 2 = female and social situation where 1 = lives alone, 2 = lives with partner/family, 3

= lives in nursing or residential home and 4 = other. Missing data were given a value of 9999 so that it could be easily identified and excluded from the analysis.

The questionnaires were evaluated for internal consistency and factorial validity. Internal consistency, or the degree to which individuals responded in a consistent way, was determined using Cronbach's alpha ( $\alpha$ ). Factorial validity was determined using principal components analysis, where the aim was to establish the degree to which the theoretical constructs of treatment beliefs and self-care were supported.

The questionnaires were examined for missing data and normal distribution. This was important in terms of the use of parametric tests such as t-tests and analysis of variance (ANOVA), described below, which assumes that scores are normally distributed. Descriptive statistics of frequencies, percentages, means, standard deviations and ranges were calculated in order to describe the socio-demographic characteristics of the sample, illness representations, treatment beliefs and self-care.

The degree of association between socio-demographic variables and self-care was tested using Chi-squared ( $X^2$ ) or ANOVA, depending on the type of variables. In determining the relationships between illness representations, treatment beliefs and self-care, Pearson's correlation co-efficients ( $r$ ) were calculated. Finally, multiple regression analysis was carried out in order to assess the extent to which the criterion variable (self-care) could be determined by the predictor variables (socio-demographic variables, illness representations and treatment beliefs).

In interpreting the results of these relationships, statistical significance was noted. Probability values ( $p$ ) indicated the likelihood of any observed differences happening by chance. The lower the  $p$  value, the less likely the difference occurred by chance and so the higher the significance of the finding.  $p \leq 0.05$  was considered an acceptable level of significance while  $p \leq 0.01$  was considered highly significant (Coolican, 2009).

## **6.2 RELIABILITY AND VALIDITY**

The consideration of the validity and reliability of the questionnaires is important in determining the overall value and the strength of the findings. Validity is the degree to which an instrument measures the attribute it was designed to measure. Reliability is the accuracy with which the instrument measures that attribute (Polit and Hungler, 2001).

Bannigan and Watson (2009) describe the measurement of reliability in terms of stability, internal consistency and equivalence. Stability describes the extent to which the same results are obtained on repeated administrations of the instrument – commonly assessed as ‘test-retest reliability’. Internal consistency considers the extent to which respondents answer related items in a similar way. Cronbach’s alpha ( $\alpha$ ) is frequently used for measuring internal consistency. Equivalence describes the use of the scale by different administrators at the same time (inter-rater reliability) or administration of two forms of the scale to the same sample, successively (alternative form reliability).

There are a number of different ways by which validity can be determined (Coolican, 2009; Tashakkori and Teddlie, 1998; De Vaus, 1996) and it is recommended that a variety of approaches are used (McDowell and Newell, 1996). Most simply, face validity is the extent to which the instrument ‘looks like’ it measures the intended attribute. However, this is considered a weak form of validity and other methods are favoured (Tashakkori and Teddlie, 1998). These are commonly referred to as content, criterion, and construct validity.

Content validity is the extent to which the instrument covers the area or content it is intended to cover. That is, it includes all relevant issues and excludes those that are not relevant. It is commonly assessed through a critical review by an expert panel or in comparison to the literature (Bannigan and Watson, 2009). Criterion validity is demonstrated when findings relate to other known data in a predictable way. It includes concurrent and predictive validity. Concurrent validity is the extent to which scores on an instrument are similar to scores on other established measures administered at the same time (for example, agreement between scores on the LAYHFQ and the EHFSBS). Predictive validity considers the extent to which the results of the scale predict expected future outcomes.

Construct validity evaluates how well the instrument conforms to theoretical expectations or constructs (De Vaus, 1996). Construct validity can be accessed through convergent/divergent, factorial and discriminant validity. Convergent/divergent validity involves formulating hypotheses about whether the scale will correlate (or not) with other measurement scales and then testing these hypotheses. Factorial validity uses the statistical procedure of factor analysis which describes the underlying or latent conceptual structures of an instrument. Factorial validity is demonstrated when items in the scale group together in a consistent and coherent way (Bowling, 1995). Discriminant validity describes the scales ability to differentiate or discriminate between groups which are expected to differ. For example, it should be able to differentiate between scores in those with different illnesses.

In this study, internal consistency was calculated for the IPQ-R (HF), the MUHFQ and the LAYHFQ using Cronbach's  $\alpha$ . Factorial validity was determined using principle components analysis (PCA). The following section presents the methods and results of this analysis. An overall evaluation of the extent to which the questionnaires can be considered reliable and valid is given in Chapter seven.

### **6.3 INTERNAL CONSISTENCY AND FACTORIAL VALIDITY OF THE QUESTIONNAIRES**

The internal consistency of the IPQ-R (HF), MUHFQ and the LAYHFQ was determined using Cronbach's alpha ( $\alpha$ ). This was calculated for the questionnaires as a whole and also the theoretically derived domains, for example, the illness representations of consequences, timeline (acute/chronic), timeline (cyclical), personal control, treatment control, and coherence. In this analysis  $\alpha > 0.70$  was described as 'good' and  $\alpha = 0.50$  to  $0.70$  was described as 'moderate' (Coolican, 2009). Internal consistency was improved, where necessary, by deleting selected items in a stepwise fashion through a process of item analysis (Coolican, 2009). This involved identifying those items which, if deleted, most improved the Cronbach's  $\alpha$ . The tables in the section present the final Cronbach's  $\alpha$  values following any described deletions.

Exploratory factor analysis was carried out to determine the underlying or latent constructs of the MUHFQ and LAYHFQ. In factor analysis, correlations between variables are calculated so that 'clusters' of items may be identified and reduced to a smaller number of factors. Principal components analysis (PCA) was used as the extraction method. PCA identifies the number of factors and assigns individual items to these dimensions (Watson and Thompson, 2006).

Prior to conducting PCA, an assessment of the suitability of the data is first required (Pallant, 2010). Sample size is important since correlations are considered to be less reliable in small samples. Specifically, the ratio between the number of cases and the number of items in the scale is important. Whilst authors vary in their recommendations, 5 cases for each item are generally considered adequate (Pallant, 2010). In the MUHFQ, the number of items is 19 so that the calculation of  $5 \times 19$  gives a required sample size of 95, which is well within the 169 cases in this analysis. The LAYHFQ has 28 items, the calculation  $5 \times 28$  gives a required sample size of 140, which again suggests that the sample size was sufficient. The second

consideration is the strengths of the correlations between variables. A preponderance of correlations above  $r = 0.3$  is considered sufficient according to Pallant (2010). A review of the correlation matrix of the MUHFQ identifies a number of correlations above  $r = 0.3$ . However, the LAYHFQ has fewer correlations of this strength. Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy are further tests for the suitability of the data for factor analysis. Pallant (2010) suggests Bartlett's test should be statistically significant ( $p \leq 0.05$ ) and the KMO index should be above 0.6. This analysis is summarised in Table 6.1 and suggests that the data from both the MUHFQ and the LAYHFQ are suitable for factor analysis.

**Table 6.1**      **Suitability of the Data for Factor Analysis**

<b>Questionnaire</b>	<b>Bartlett's test of Sphericity</b>	<b>Kaiser-Meyer-Olkin index</b>
MUHFQ	$p < 0.001$	0.76
LAYHFQ	$p < 0.001$	0.69

Kaiser's Criterion, Catell's Scree test and Horn's parallel analysis were used in combination to determine the number of factors in this analysis. Using Kaiser's criterion, eigenvalues represent the amount of the total variance explained by any factor. An eigenvalue  $>1.0$  indicates that the factor explains more of the variance than the original items. Therefore, only those factors with an eigenvalue  $>1.0$  should be retained. The scree test plots each of the eigenvalues against the number of items. The point at which the slope breaks (the 'elbow') is identified and all factors above this point should be retained. However, both Kaiser's criterion and the scree test have been criticised for their tendency to overestimate the number of factors (Pallant, 2010).

Parallel analysis is considered to be a more accurate method of determining factors (Pallant, 2010). This involves comparing the size of the actual eigenvalues against those of randomly generated data sets of the same size. In this case, 100 data sets were generated using the parallel analysis software MonteCarloPA ([www.softpedia.com](http://www.softpedia.com)). Only those factors with eigenvalues above the corresponding values of the generated data set should be retained.

Although Kaiser's criterion, the scree test and parallel analysis were used to estimate the number of factors, the final number was determined according to the judgement of the researcher as advocated by Watson and Thompson (2006).

The process of rotation was used to assist in the interpretation of the number of factors. The purpose of rotation is to maximise the loadings or correlations of items. In this study, Varimax rotation was used which attempts to minimise the number of variables that have high loading on each factor (Pallant, 2010). This is a commonly used orthogonal approach, meaning that it is assumed that the factors derived are not correlated with each other. The aim was to identify a simple structure with each item loading strongly on only one factor, whilst minimising the loading of items onto other factors (cross-loading). Loadings above 0.45 were considered significant (Dancey and Reidy, 2007).

The final step in PCA was to describe and label the resulting factors. Here, themes developed from the qualitative interviews were used to describe the underlying constructs as indicated by factor analysis.

### 6.3.1 The IPQ-R (HF)

Table 6.2 presents the internal consistency of the domains of the IPQ-R (HF) and the questionnaire as a whole.

**Table 6.2**      **Internal Consistency of the IPQ-R (HF)**

Domain	Number of items (n)	Cronbach's $\alpha$
Timeline (acute/chronic)	6	0.80
Consequences	6	0.70
Personal control	6	0.78
Treatment control	4	0.70
Timeline (cyclical)	4	0.82
Coherence	5	0.71
Emotional response	6	0.88
IPQ-R (HF) (Total)	37	0.74

Internal consistency of the timeline (acute/chronic) domain, using the original IPQ-R items was good at  $\alpha = 0.80$ . The additional timeline items, '*My heart failure will get worse in time*' (IPN1) and '*I expect my heart failure to stay the same in the future*' (IPN2), were added separately and together but reliability was not improved (IPN1 only,  $\alpha = 0.79$ , IPN2 only,  $\alpha = 0.71$ , IPN1 plus IPN2,  $\alpha = 0.71$ ). Therefore, in the subsequent data analysis only the 6 original IPQ-R timeline items were included.

The domains of personal control ( $\alpha = 0.78$ ), timeline (cyclical) ( $\alpha = 0.82$ ), coherence ( $\alpha = 0.71$ ) and emotional response ( $\alpha = 0.88$ ) also demonstrated good internal consistency. The consequences sub-scale demonstrated moderate but acceptable internal consistency ( $\alpha = 0.70$ ).

Treatment control, on initial analysis, demonstrated only moderate internal consistency ( $\alpha = 0.57$ ). In order to improve the reliability of this sub-scale, inter-item correlations were calculated. The item '*My treatment will be effective in curing my heart failure*', had limited correlation with other items. Theoretically, in chronic illness, the term 'cure' may be inappropriate and may explain the lack of correlation between this and other items in this sub-scale. Internal consistency was improved to an acceptable level of  $\alpha = 0.70$  when this item was deleted. This item was therefore, excluded in subsequent analysis.

Reliability of the IPQ-R (HF) as a whole was good ( $\alpha = 0.74$ ). Factorial validity was not assessed in this questionnaire as changes from the IPQ-R were minimal and this questionnaire has been extensively psychometrically tested in a number of illness groups (Moss-Morris et al, 2002).

### 6.3.2 The MUHFQ

Table 6.3 presents the internal consistency of the domains of the MUHFQ.

**Table 6.3**      Internal Consistency of the MUHFQ

Domain	Number of items (n)	Cronbach's $\alpha$
Necessity	5	0.74
Concerns	4	0.76
Medication knowledge	4	0.73
Social influences on medication use	3	0.74
Impact of medication use on lifestyle	3	0.56

Necessity of medication using the original items from the BMQ achieved good internal consistency ( $\alpha = 0.74$ ). When the additional necessity item, '*My symptoms improve when I take my tablets*', was added, reliability was not improved ( $\alpha = 0.73$ ) so this item was not included in further analysis.



On reflection, the BMQ concern item, '*My tablets disrupt my life*', seemed to relate more to the impact of medication use on lifestyle sub-scale and so was analysed as such. The concerns sub-scale, therefore, consisted of the remaining BMQ concern items and the additional item, '*I sometimes worry about the effect of taking lots of different tablets*'. Internal consistency using these items was good at  $\alpha = 0.76$ .

The medication knowledge sub-scale initially showed moderate internal consistency of  $\alpha = 0.65$ . Determination of inter-item correlations showed that the item, '*I am unsure whether I should take medication that I buy myself with my heart failure tablets*' had limited correlation with the other items. The reason for this may be that this question was complex and reversed and so may have been poorly understood. This is supported by the discussions with the heart failure clinic patients who reported that they found complex, reversed questions more difficult to answer. Alternatively, as this question relates to other medications, not just those for heart failure, it may not be measuring the same construct as the other items in this domain which relate specifically to knowledge about heart failure medication. With this item deleted, reliability of this sub-scale was improved to  $\alpha = 0.73$ . This item was therefore, excluded in further analysis.

Social influences on medication use showed good internal consistency of  $\alpha = 0.74$ . However, the impact of medication use on lifestyle scale demonstrated only moderate internal consistency ( $\alpha = 0.52$ ). Inter-item correlations showed that reliability was improved to a small degree by excluding the item, '*Taking my tablets is part of my daily routine*' ( $\alpha = 0.56$ ). As the only reversed item in this sub-scale this may have been answered inconsistently. This item was subsequently omitted in further analysis. Further step-wise deletions did not improve the reliability and it should, therefore, be noted that this sub-scale achieved only moderate reliability in this sample and so the conclusions drawn in relation to these findings are necessarily tentative.

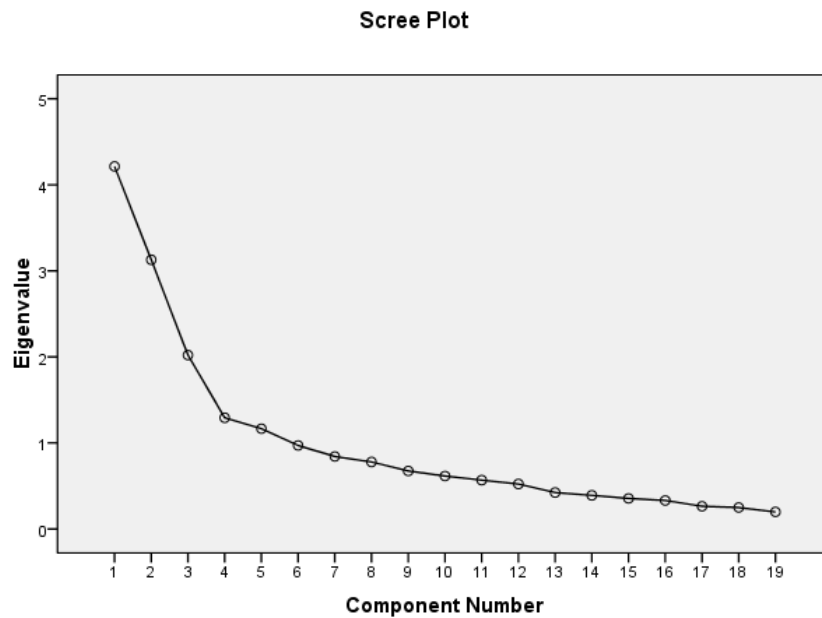
Internal consistency of the whole questionnaire was not calculated as the necessity and concerns domains could be viewed as opposing beliefs and so tended to cancel each other out. Horne et al (1999) similarly, did not report the internal consistency of the BMQ as a whole.

Principal components analysis (PCA) of the MUHFQ revealed the presence of 5 factors with eigenvalues  $>1.0$  according to Kaiser's criterion - F1, 4.21; F2, 3.13; F3, 2.02; F4, 1.23; F5, 1.17. These factors explained 62.22% of the variance in the MUHFQ scores. F1, the first

principal component, explained 22.18% of the variance, F2 16.47%, F3 10.63%, F4 6.80% and F5 6.14%.

The scree test illustrates a break after the fourth component (Figure 6.1), Suggesting a 4-factor structure.

Figure 6.1      Scree Plot of the MUHFQ



Parallel analysis showed 3 components with eigenvalues exceeding the corresponding values from 100 randomly generated data set (Table 6.4)

Table 6.4      Parallel Analysis of the MUHFQ

Component Number	Actual Eigenvalue	Eignenvale from parallel analysis
1	4.214	1.663
2	3.129	1.518
3	2.020	1.423
4	1.292	1.341

In determining the number of factors, a judgement needed to be made about the meaning of these constructs. The 5 factors corresponded to the theoretical domains of the MUHFQ derived from analysis of the interview data. Factor 1 corresponded to the domain of

medication knowledge, Factor 2 to the concerns domain of the BMQ, Factor 3 to necessity beliefs, Factor 4 to social influences on medication use and Factor 5 to the impact of medication use on lifestyle domains. Therefore, the decision was made to adopt this 5-factor structure, although the factors of social influences of medication use and the impact of medication use on lifestyle, especially, should be viewed with some caution. Table 6.5 shows this 5-factor structure using Varimax rotation.

**Table 6.5**      **Principal Components Analysis of the MUHFQ**

Item	Communality	First Unrotated Principal Component	Derived varimax factor solution factors				
			1	2	3	4	5
My health depends upon my tablets	0.53	0.52	0.22	-0.09	<b>0.68</b>	-0.06	0.01
Life would be impossible without my tablets	0.65	0.28	0.11	0.22	<b>0.72</b>	0.24	-0.05
Without my tablets I would be very ill	0.66	0.28	-0.05	0.20	<b>0.72</b>	0.12	-0.28
My future health depends on my tablets	0.52	0.40	0.14	0.04	<b>0.69</b>	-0.06	0.15
My symptoms improve	0.53	0.63	0.43	-0.11	<b>0.56</b>	-0.12	0.02
I worry about long-term side-effects	0.64	-0.20	0.012	<b>0.77</b>	0.01	0.17	-0.06
I worry about becoming dependent	0.48	-0.14	-0.01	<b>0.67</b>	0.09	0.01	0.13
My tablets protect me from becoming worse	0.61	-0.26	-0.28	<b>0.71</b>	0.05	-0.12	-0.02
I worry about the effects of lots of tablets	0.68	-0.15	0.06	<b>0.82</b>	-0.02	-0.01	0.07
I understand why I need my tablets	0.74	0.76	<b>0.80</b>	-0.09	0.24	-0.12	-0.05
I know when to take my tablets	0.71	0.76	<b>0.77</b>	0.04	0.19	-0.26	-0.10
I know the dose of my tablets	0.74	0.77	<b>0.76</b>	0.04	0.16	-0.34	-0.09
I am clear about my symptoms/tablets	0.46	0.42	<b>0.59</b>	-0.12	0.05	0.22	-0.18
I am influenced by my family or friends	0.50	-0.36	-0.00	0.05	-0.01	<b>0.66</b>	0.24
I would find it difficult without help	0.69	-0.46	-0.30	0.01	0.10	<b>0.76</b>	-0.07
I follow the advice of family or friends	0.70	-0.42	-0.08	0.06	0.00	<b>0.83</b>	0.03
My tablets disrupt my life	0.58	-0.30	-0.03	<b>0.53</b>	0.11	0.24	<b>0.46</b>
I find it difficult to take tablets when I go out	0.71	-0.37	-0.22	0.08	0.05	0.00	<b>0.80</b>
My lifestyle prevents me from taking my tablets	0.61	-0.59	-0.15	0.05	-0.36	0.36	<b>0.57</b>

Cross-loading was apparent with the item '*My tablets disrupt my life*' loading onto F3 - concerns (0.53) and F5 - impact of medication use on lifestyle (0.46). As this item was part of the original concerns sub-scale on the BMQ, this is perhaps not surprising and demonstrates a close relationship between general concerns about medication and the impact of medication use on lifestyle which may be considered to be a specific, practical concern.

### 6.3.3 The LAYHFQ

Table 6.6 presents the internal consistency of the domains of the LAYHFQ and the questionnaire as a whole.

**Table 6.6**      **Internal Consistency of the LAYHFQ**

Domain	Number of items (n)	Cronbach's $\alpha$
Lifestyle adherence	5	0.13
Medication adherence	7	0.54
Monitoring	7	0.76
Managing symptoms, social and emotional effects	5	0.48
Reporting and seeking help	4	0.50
LAYHFQ (Total)	28	0.77

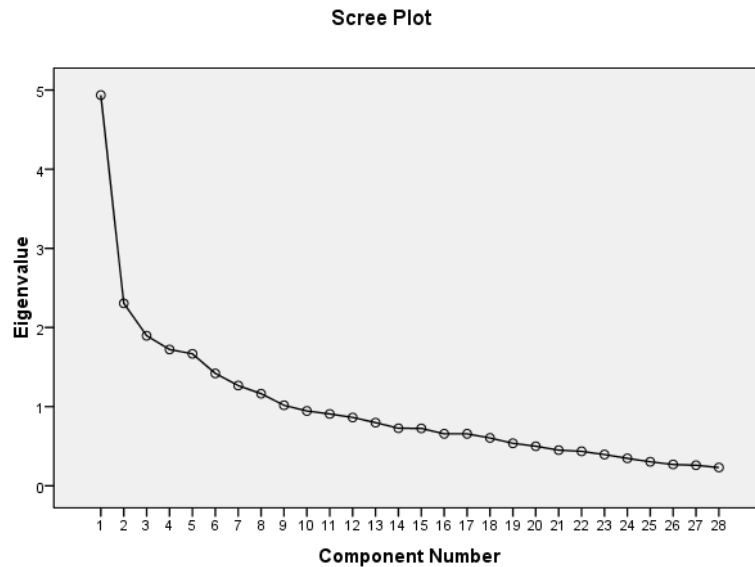
Medication adherence ( $\alpha = 0.54$ ), reporting and seeking help ( $\alpha = 0.50$ ) and monitoring ( $\alpha = 0.76$ ), demonstrated moderate to good internal consistency. Adherence to recommended lifestyle behaviours and managing symptoms and the social and emotional effects of the illness, did not demonstrate satisfactory internal reliability ( $\alpha < 0.50$ ). Step-wise deletion did not significantly improve this. As a result, overall, the individual domains of the LAYHFQ cannot be considered sufficiently internally reliable for use in this analysis. However, the internal consistency of the LAYHFQ when taken as a whole was good at  $\alpha = 0.77$ . Therefore, in subsequent analysis, a total self-care score was used rather than individual domains. The implication of this is that relationships between beliefs and specific self-care behaviours, such as medication adherence, could not be determined. However, it is worth noting that internal consistency of the EHFScBS was also only demonstrated when self-care was taken as a total score (Jaarsma et al, 2003).

Principal components analysis (PCA) of the LAYHFQ revealed the presence of 9 factors with eigenvalues  $>1.0$ . (F1, 4.94; F2, 2.31; F3, 1.90; F4, 1.72; F5, 1.67, F6 1.42, F7, 1.27, F8,

1.16, F9, 1.02). These factors explained 62.12% of the variance in the LAYHFQ scores. F1, the first principal component, explained 17.63%, F2 8.23%, F3 6.77%, F4 6.15%, F5 6.01%, F6 5.96%, F7 5.07%, F8 4.52% and F9 3.61%.

The scree test is difficult to more interpret but indicates a break after the second component (Figure 6.2) with a smaller break after the fifth component.

**Figure 6.2**      **Scree plot of the LAYHFQ**



Parallel analysis showed 6 components with eigenvalues exceeding the corresponding values from 100 randomly generated data set (Table 6.7).

**Table 6.7**      **Parallel Analysis of the LAYHFQ**

Component Number	Actual Eigenvalue	Eigenvalue from parallel analysis
1	4.936	1.837
2	2.305	1.718
3	1.896	1.620
4	1.722	1.530
5	1.668	1.460
6	1.419	1.397
7	1.163	1.270

Based on Kaiser's criterion, Table 6.8 presents the 9 factor solution.

**Table 6.8**      **Principal Components Analysis of the LAYHFQ**

Item	Communality	First Unrotated Principal Component	Derived varimax factor solution factors								
			1	2	3	4	5	6	7	8	9
Exercise	0.54	0.05	0.05	-0.08	<b>0.56</b>	0.17	0.30	-0.08	-0.11	0.07	-0.05
Smoking	0.51	0.04	0.04	-0.11	0.30	0.36	0.42	0.28	0.10	0.04	0.07
Fluids	0.54	0.16	0.16	-0.01	-0.06	-0.19	0.22	0.26	0.45	-0.38	-0.05
Salt	0.75	0.35	0.35	0.16	0.31	0.05	-0.13	0.29	-0.32	-0.49	0.20
Alcohol	0.64	0.22	0.22	0.10	0.45	0.22	-0.23	-0.32	0.36	0.05	-0.15
Flu Jab	0.57	0.43	0.43	0.29	0.17	0.12	-0.31	-0.15	-0.00	-0.33	-0.013
Forget to take tablets	0.66	0.39	0.39	0.18	0.22	0.29	-0.13	0.19	0.22	-0.01	-0.48
Choose not to take tablets	0.47	0.43	0.43	0.24	-0.12	0.35	0.08	-0.22	0.01	0.13	-0.11
Change dose as instructed	0.63	0.57	<b>0.57</b>	-0.42	-0.12	0.23	0.11	0.06	-0.03	-0.15	0.04
Change dose	0.63	0.50	<b>0.59</b>	-0.29	-0.27	0.22	0.01	-0.24	0.01	-0.05	0.04
Change time	0.68	0.67	<b>0.67</b>	-0.35	-0.15	0.24	0.08	-0.10	0.01	0.02	-0.08
Collect prescriptions	0.63	0.62	<b>0.62</b>	-0.22	-0.31	0.19	0.08	0.07	0.19	0.07	0.08
Weighing	0.56	0.57	<b>0.57</b>	-0.18	-0.02	-0.05	0.17	-0.25	-0.02	-0.15	0.14
Monitor sleeping	0.67	0.38	0.38	-0.28	0.32	-0.47	0.10	-0.07	-0.07	0.30	0.04
Monitor tiredness	0.74	0.43	0.43	-0.42	0.20	-0.03	0.10	0.18	0.07	0.40	-0.16
Monitor breathing	0.61	0.59	<b>0.59</b>	-0.30	0.20	-0.10	0.01	0.23	-0.16	-0.14	0.07
Monitor cough	0.58	0.62	<b>0.62</b>	0.01	0.01	-0.18	-0.31	-0.20	-0.02	-0.01	0.13
Monitor fluid	0.50	0.41	0.41	0.33	0.09	-0.19	-0.21	-0.34	0.04	-0.05	0.02
Recognise tablet effects	0.60	0.45	0.45	0.23	0.09	-0.18	-0.42	0.05	0.09	0.30	0.12
Keep active	0.61	0.55	<b>0.55</b>	0.07	0.23	-0.03	-0.12	0.29	-0.05	-0.03	0.05
Go out	0.57	0.13	0.13	0.24	-0.22	0.08	-0.15	0.52	0.36	0.08	0.05
Positive attitude	0.61	0.28	0.28	0.34	-0.18	0.34	-0.06	0.05	-0.16	0.34	0.32
Meet family/friends	0.61	0.28	0.28	<b>0.51</b>	-0.22	-0.18	0.36	-0.01	0.23	0.01	-0.01
Rest	0.63	0.37	0.37	<b>0.48</b>	-0.17	0.05	0.15	0.25	-0.26	0.22	-0.11
Report changes	0.67	0.43	0.43	0.44	0.01	-0.01	0.29	0.10	-0.40	-0.01	-0.12
Report effects	0.69	0.15	0.15	0.27	-0.20	-0.39	<b>0.46</b>	-0.27	-0.09	-0.11	-0.28
Report OTC	0.72	-0.08	-0.08	0.18	<b>0.53</b>	0.30	0.33	-0.18	0.01	0.05	0.40
Seek advice	0.63	0.17	0.17	0.26	0.20	-0.20	0.034	-0.09	0.44	-0.04	0.35

Reduction to 5 factors, according to the proposed theoretical domains of self-care, did not significantly improve loading. This analysis is presented in Appendix 24.

Jaarsma et al (2003) also found that the theoretical domains of self-care were not supported by factor analysis of the EHFS CBS. It is, therefore suggested from the analysis of the LAYHFQ and the EHFS CBS, that the behaviours that make up self-care may be separate, from a patient perspective. For example, taking regular exercise or making dietary changes may be perceived as being part of a healthy lifestyle and not necessarily behaviours carried out in response to the heart failure. This was also suggested by the qualitative data. As a result, such behaviours may not be easily grouped together as they are likely to be influenced by a range of individual factors. This is discussed further in Chapter seven.

## **6.4 RESULTS**

### **6.4.1 The response rate**

At the end of the data collection period, Site A had delivered 180 questionnaires as anticipated. At Site B, distribution was more problematic as due to staff changes and holidays, only 25 of the 90 allocated questionnaires were distributed. Site C distributed 130 of the 180 allocated which was the total available population at that time. This meant that overall, a total of 335 sets of questionnaires were delivered, 133 fewer than anticipated.

However, 169 sets of questionnaires were completed representing a response rate of 50.4%. The target sample size of 156 responses was, therefore, achieved. This response rate, though lower than in the pilot study (60%) was nevertheless sufficient according to the power calculation and higher than the one-third suggested by De Vaus (1996).

The majority ( $n = 152$ , 89.9%) of participants elected to self-complete the questionnaires, as indicated by the pilot study. This suggests that participants were able to understand the instructions for completion and were able to answer the questions. However, it does not guarantee that family members or friends did not complete the questionnaires or that the questions were fully understood. Fourteen participants (8.3%) chose to complete the questionnaires by face-to-face interview, (thirteen in Site A, one in Site C), with three participants in Site A (1.8%) opting to complete the questionnaires by telephone. Differences in socio-demographic characteristics between these three sites are presented in the following section.

#### **6.4.2 Socio-demographic and illness-related characteristics of the sample**

In describing the socio-demographic and illness-related characteristics of age and time with the illness, the mean or average score, standard deviation (SD) or spread of dispersion around the mean and range (maximum and minimum scores) were calculated (Harris and Taylor, 2008). Gender, ethnic origin, social situation, education, occupation, the presence of co-morbidities and functional ability as classified by the NYHA, were described in terms of frequencies or the number of times an observation occurred, and presented as percentages (Table 6.9)

The mean age of the sample was 70.89 years (range 30-91, SD  $\pm$  11.99). The mean time with the illness was 7.34 years (range 0.1-70, SD  $\pm$  9.39). 74.1% of the sample were men and 25.9% were women. All participants described themselves as of White, British ethnic origin. The majority of the sample (79.5%) lived with a partner or family with 19.3% living alone. Just over half the participants (54.9%) had no formal qualifications. Most were retired (80%). A high proportion, 71.6%, had co-morbidities such as renal disease or diabetes, for example. According to the NYHA functional classification, most participants classified themselves as either class II or III which represents moderate severity of heart failure.



**Table 6.9**      **Socio-Demographic and Illness-Related Characteristics of the Sample**

	<b>Number of Responses (n)</b>	<b>Range</b>	<b>Mean</b>	<b>SD (±)</b>
Age (years)	165	30-90	70.89	11.99
Time with Illness (years)	157	0.1-70	7.34	9.39
	<b>Number of Responses (n)</b>	<b>Frequency</b>	<b>%</b>	
Gender	166			
Male		123	74.1	
Female		43	25.9	
Ethnic Origin	165			
White, British		165	100.0	
Social Situation	166			
With partner/family		132	79.5	
Lives alone		32	19.3	
Residential/nursing		2	1.2	
Qualifications	162			
None		89	54.9	
GCSE 'O'level		31	19.1	
'A' level		11	6.8	
Degree		14	8.6	
Post-graduate		6	3.7	
Other		11	6.8	
Occupation	165			
Retired		132	80.0	
Employed		20	12.1	
Homemaker		7	4.2	
Unemployed		3	1.8	
Medically retired		3	1.8	
Co-morbidities	169			
Yes		121	71.6	
No		48	28.4	
NYHA classification	146			
I		28	19.2	
II		38	26.0	
III		52	35.6	
IV		28	19.2	

The socio-demographic and illness-related characteristics of participants from each of the three sites were examined to determine the extent to which the sample could be considered

homogenous or coming from a single population. The degree of association between the categorical variables of site and gender, social situation, level of education, occupation, presence of co-morbidities and NYHA classification was tested using Chi-Squared ( $X^2$ ).  $X^2$  measures the difference between observed and expected frequencies with the assumption that there is no difference between the variables - the null hypothesis. In this case the null hypothesis was that there was no difference in terms of socio-demographic or illness-related characteristics between the different sites.

However, with the exception of gender and co-morbidities, there were too few cases to include Site B in this analysis ( $n = 7$ ). At Sites A and C, there were too few cases in some categories of social situation, occupation and qualifications to make  $X^2$  analysis reliable. Therefore, those categories were either omitted from the analysis or categories were combined as follows: The social situation category of '*live in a nursing or residential home*' ( $n = 1$ ) was excluded. Similarly, in terms of occupation, the categories of '*unemployed*' ( $n = 2$ ) and '*homemaker*' ( $n = 3$ ) were also excluded. Qualifications were grouped into two categories - those with and those without formal qualifications. On interpretation of this analysis an associated p value gave the statistical significance or likelihood that the difference could have occurred by chance. Degrees of freedom (df) indicated the number of independent variables (Table 6.10).

There were no statistically significant differences in terms of gender, social situation, qualifications, the presence of co-morbidities or NYHA scores between Sites A and C. In terms of occupation there was a statistically significant difference, with Site C having a higher than expected number of employed respondents ( $X^2 = 4.32$ ,  $df = 1$ ,  $n = 146$ ,  $p = 0.04$ ).

**Table 6.10**      Differences Between Sites in Terms of Socio-Demographic and Illness-Related Characteristics

<b>Variable</b>	<b>Number of Responses (n)</b>	<b>Chi-Square (<math>X^2</math>)</b>	<b>df</b>	<b>p</b>
Gender	166	0.78	2	0.67
Social Situation	157	1.02	1	0.30
Qualifications	149	1.42	2	0.49
Occupation	146	4.32	1	0.04*
Co-morbidities	169	3.09	2	0.21
NYHA	143	0.14	3	0.99

In relation to the continuous variables of age and time with illness across the three sites, one

way Analysis of Variance (ANOVA) was carried out. Unlike  $X^2$ , in ANOVA the variation around the means are compared rather the frequencies. The F value gives a measure of the variance between groups, compared to within groups. On analysis, there were no statistically significant differences in terms of age (F, 0.40,  $p = 0.67$ ) or time with illness (F, 0.08,  $p = 0.92$ ) across the three sites (Table 6.11).

**Table 6.11** Differences Between Sites in Terms of Age and Time with Illness

Variable	Sum of squares	df	Mean square	F	p
Age (years)	117.07	2	58.54	0.40	0.67
Time with Illness (years)	14.35	2	7.18	0.08	0.92

Although, methodologically, it may have been useful to determine if there were differences in socio-demographic or illness-related characteristics between participants opting for different methods of data collection, too few interview cases were available for meaningful analysis.

In conclusion, with the exception of occupation, no significant differences were found in the socio-demographic or illness-related characteristics of participants in Sites A and C, so that it can be concluded that these samples can be considered to come from a single population.

#### 6.4.3 Illness representations and emotional response

The domains of illness representations were described in terms of mean scores, standard deviations, and ranges. One-sample t-tests (2-tailed) were carried out to determine whether the means were statistically different from the neutral score of zero. A value of  $p \leq 0.05^*$  was considered significant. This analysis is presented in Table 6.12.

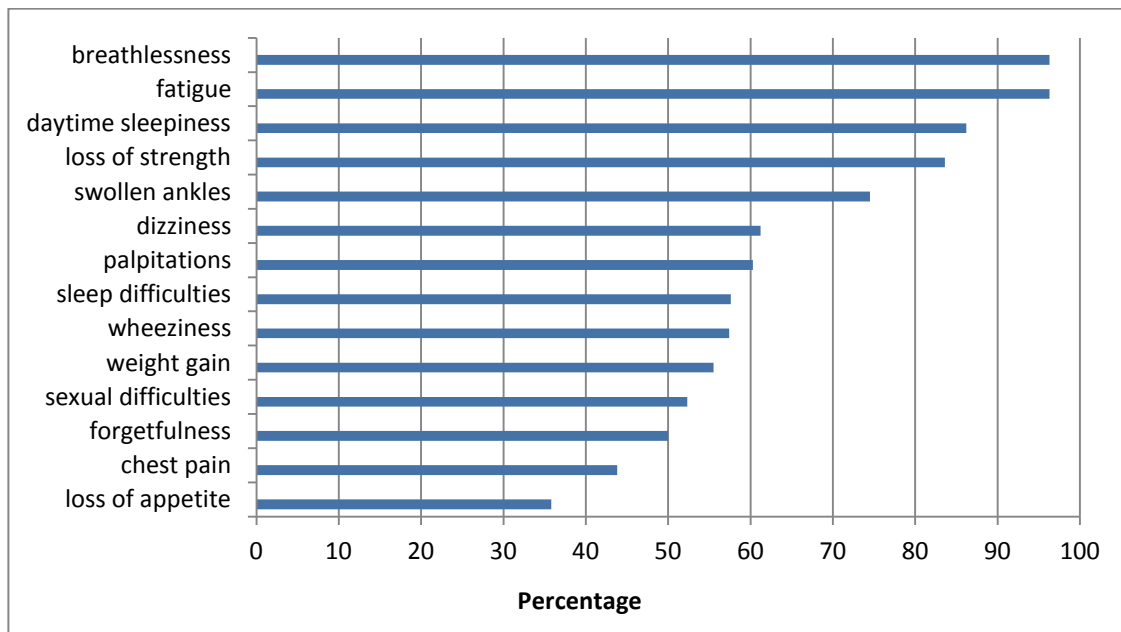
**Table 6.12** Illness Representations and Emotional Response

Domain	Number of Responses (n)	Mean Score	Range	SD ( $\pm$ )	p
Identity	96	9.14	0 to 15	2.99	n/a
Timeline (acute/chronic)	136	6.09	-12 to 12	3.88	<0.001*
Consequences	138	2.98	-12 to 12	3.89	<0.001*
Personal Control	138	3.20	-12 to 12	4.08	<0.001*
Treatment Control	144	2.35	-8 to 8	2.63	<0.001*
Timeline (cyclical)	145	-0.96	-8 to 8	2.48	<0.001*
Coherence	147	2.40	-10 to 10	3.87	<0.001*
Emotional response	146	-0.17	-12 to 12	5.33	0.698

In the identity domain, a high number of symptoms were believed to be associated with heart failure (mean number of symptoms 9.14, SD  $\pm$  2.99). There was a strong belief that the illness had a chronic timeline (mean 6.08, SD  $\pm$  3.88, range -12 to +12,  $p = <0.001$ ), and had serious consequences (mean 2.98, SD  $\pm$  3.89, range -12 to +12,  $p = <0.001$ ). The degree of control over the illness was reportedly high both in terms of personal control (mean 3.20, SD  $\pm$  4.08, range -12 to +12,  $p = <0.001$ ) and treatment control (mean 2.35, SD  $\pm$  2.63, range -8 to +8,  $p = <0.001$ ). There was a high level of reported illness coherence, indicating agreement that the illness 'made sense' (mean 2.40, SD  $\pm$  2.43, range -10 to +10,  $p = <0.001$ ). Symptoms were not viewed as cyclical or episodic (mean -0.96, SD  $\pm$  3.87, range -8 to +8,  $p = <0.001$ ) and although few negative emotional responses were reported, this was not statistically significant (mean -0.17, SD  $\pm$  5.33, range -12 to +12,  $p = 0.698$ ).

In relation to symptoms, breathlessness and fatigue were most widely described with 96.3% of the sample reporting these symptoms. Daytime sleepiness (86.2%), loss of strength (83.6%), swollen ankles (74.5%), dizziness (61.2%), palpitations (60.3%), sleep difficulties (57.6%), wheeziness (57.4%), weight gain (55.5%), sexual difficulties (52.3%) and forgetfulness (50.0%) were described by at least half the participants. Chest pain (43.8%) and loss of appetite (35.8%) were least frequently experienced (Figure 6.3).

**Figure 6.3** Percentages of Specific Symptoms Attributed to Heart Failure



From the open question, other diverse symptoms of heart failure were reported including hallucinations, cramp, numbness in the arms, heaviness in the legs, tremors, hot sweats and

falls. A cough was reported by three participants. Negative emotions such as depression, anxiety, panic attacks and ill temper were also identified as symptoms by ten participants, indicating the difficulty in categorising negative emotions as either symptoms or responses. There was an overall lack of agreement that the heart failure was due to the suggested causes (Table 6.13).

**Table 6.13**     **Beliefs about Causation**

<b>Cause</b>	<b>Number of Responses (n)</b>	<b>Mean</b>	<b>SD (<math>\pm</math>)</b>	<b>p</b>
Ageing	154	0.27	1.09	0.002*
Stress or worry	148	0.07	1.21	0.455
High blood pressure	149	-0.01	1.24	0.895
Hereditary	148	-0.15	1.21	0.121
Other illnesses	146	-0.20	1.11	0.033*
Chance/bad luck	146	-0.23	1.04	0.008*
Overwork	148	-0.28	1.06	0.001*
Other heart problems	147	-0.29	1.14	0.002*
Overweight	148	-0.32	1.15	0.001*
Previous heart attack	147	-0.35	1.28	0.001*
Diet/eating habits	146	-0.36	1.07	<0.001*
Smoking	150	-0.42	1.30	<0.001*
Family problems/worries	146	-0.52	1.02	<0.001*
Treatment for other illnesses	143	-0.63	1.00	<0.001*
An infection	140	-0.66	0.95	<0.001*
Poor medical care in the past	146	-0.80	0.97	<0.001*
Alcohol	150	-0.93	0.97	<0.001*

The only statistically significant cause which was positively identified was ageing (mean 0.27, range -2 to +2, SD  $\pm$  1.09, p = 0.002). There was also agreement that the illness was caused by stress or worry, but this was not statistically significant (mean 0.07, SD  $\pm$  1.21, range -2 to +2, p = 0.455). Most other causes such as a previous heart attack or smoking, for example, were not perceived as the cause of the illness. Two additional causative factors were identified in the open question, pregnancy and loneliness, each of which was cited only once.

In summary, heart failure was seen as a long-term condition with serious consequences. Participants believed that the illness could be controlled by medication as well as reporting a high degree of personal control. The illness was described a 'making sense' and participants

did not commonly experience negative emotions such as depression or anxiety as a result of having heart failure, which is in contrast to the interview findings. However, these emotions were described as a symptom rather than a response to the illness by a small number of participants (n = 10). A high number of diverse and debilitating symptoms which were believed to be due to heart failure were reported, with breathlessness and fatigue almost universally cited. In contrast to the biomedical model of heart failure, lifestyle factors and CHD were not perceived to be the cause of the illness with only ageing and stress or worry, positively identified as causative factors. These results are discussed in Chapter seven.

#### 6.4.4 Treatment beliefs

Treatment beliefs are described in Table 6.14.

Table 6.14    Treatment Beliefs

Domain	Number of Responses (n)	Mean	Range	SD (±)	p
Necessity	159	4.96	-10 to 10	2.56	<0.001*
Concerns	153	0.17	-8 to 8	3.14	0.016*
Medication Knowledge	156	4.21	-10 to 10	2.59	<0.001*
Social influences on medication use	154	-2.74	-6 to 6	2.40	<0.001*
Impact of medication use on lifestyle	154	-2.40	-6 to 6	1.96	<0.001*

Overall, there was a positive attitude to the use of medication with strong necessity beliefs (mean 4.96, SD  $\pm$  2.56, range -10 to +10, p = <0.001), reportedly good medication knowledge (mean 4.21, SD  $\pm$  2.59, range -10 to +10, p = <0.001), few concerns (mean 0.17, SD  $\pm$  3.14, range -8 to +8, p = 0.016) and limited impact on lifestyle reported (mean -2.40, SD  $\pm$  1.96, range -6 to +6, p = <0.001). Medication use was not believed to be influenced by family or friends (mean -2.74, SD  $\pm$  2.40, range -6 to +6, p = <0.001). These results are discussed in Chapter seven.

#### 6.4.5 Self-care

Self-care behaviours were descriptively analysed for means and SD. Scores for all items ranged from -2 to +2. Again, one-sample t-tests were used to determine statistical significance from the neutral point of zero (Table 6.15)

**Table 6.15**     **Individual Self-Care Behaviours**

<b>Domain</b>	<b>Behaviour</b>	<b>Mean Score</b>	<b>SD (±)</b>	<b>p</b>
<b>Lifestyle adherence</b>	Taking regular exercise	0.13	1.12	0.886
	Not smoking	1.55	0.92	<0.001*
	Restricting fluid intake	0.48	1.07	<0.001*
	Limiting salt intake	0.91	0.92	<0.001*
	Restricting alcohol	1.26	1.01	<0.001*
<b>Medication adherence</b>	Flu and pneumonia vaccination	1.05	0.94	<0.001*
	Forgetting (unintentional non-adherence)	-0.83	1.03	<0.001*
	Choosing not to take medication	-1.23	0.84	<0.001*
	Choose to change the dose	-1.32	0.71	<0.001*
	Choose to change the time	-0.67	1.11	<0.001*
	I collect my prescriptions so I do not run out of tablets	1.30	0.61	<0.001*
<b>Monitoring</b>	Regular weighing	0.98	0.82	<0.001*
	Recognising changes in sleep patterns	0.81	0.80	<0.001*
	Recognising if more tired than usual	0.99	0.59	<0.001*
	Recognising changes in breathing	1.06	0.56	<0.001*
	Recognising the development of a cough	1.03	0.69	<0.001*
	Recognising signs of fluid retention	1.07	0.69	<0.001*
	Recognising the effects of tablets	0.63	0.87	<0.001*
<b>Managing symptoms, emotions and social effects</b>	I am not as active as I could be	0.67	1.00	<0.001*
	Going out as much as I can	0.80	0.82	<0.001*
	Positive outlook	1.02	0.74	<0.001*
	Making an effort to see family and friends	0.97	0.71	<0.001*
	Rest when I need to	1.08	0.56	<0.001*
<b>Reporting and seeking help</b>	Reporting changes in health	0.41	1.08	<0.001*
	Reporting effects of medication	0.74	0.78	<0.001*
	Checking before taking other medication	0.85	0.84	<0.001*
	Seeking advice if questions or concerns	1.08	0.66	<0.001*

There was a high level of agreement for all recommended self-care behaviours in all domains. Only the lifestyle adherence item of taking regular exercise was not significantly significant ( $p = 0.886$ ). Participants reported high levels of medication adherence with forgetfulness, choosing not to take medication or changing the dose or time, infrequently described. As a result, the total self-care score was high in this sample (mean 24.64, SD  $\pm$  8.75, range -52 to +52,  $p = <0.001$ ). These results are discussed further in Chapter seven.

#### **6.4.6 Relationships between socio-demographic and illness-related characteristics and self-care**

From the literature a number of relationships between socio-demographic and illness-related factors and self-care were hypothesised. Higher education level and high levels of social support were expected to enhance self-care. Conversely, low economic status and the presence of co-morbidities may limit self-care. Gender and age may be related to self-care but there is conflicting evidence in relation to the nature of the relationship. Similarly, increased severity of heart failure, as measured by the NYHA, may be either a motivating or limiting factor in self-care.

In this analysis, categorical variables of socio-demographic and illness-related characteristics were analysed for their relationship to self-care using Chi-squared ( $X^2$ ). Self-care was first converted into a categorical variable by dividing total scores either side of the median of 23.00. Scores  $\leq 23.00$  were categorized as low self-care and those  $>23.00$ , high self-care. The median was chosen so that categories were equal and frequencies were sufficiently high for  $X^2$  analysis. As described in section 6.4.2, socio-demographic categories with too few cases were excluded or combined.

Following this analysis, no statistically significant relationships were found between self-care and gender ( $X^2 = 0.10$ ,  $df = 1$ ,  $p = 0.75$ ), the presence of co-morbidities ( $X^2 = 0.59$ ,  $df = 1$ ,  $p = 0.44$ ), NYHA classification ( $X^2 = 2.04$ ,  $df = 2$ ,  $p = 0.56$ ), social situation ( $X^2 = 0.13$ ,  $df = 1$ ,  $p = 0.720$ ), qualifications ( $X^2 = 0.56$ ,  $df = 1$ ,  $p = 0.45$ ) or occupation ( $X^2 = 0.01$ ,  $df = 1$ ,  $p = 1.00$ ).

In relation to the continuous variables of age and time with the illness and self-care, Pearson's correlation co-efficients ( $r$ ) were calculated. Correlation considers the extent to which there is a linear relationship between two variables, although it does not indicate cause and effect. An example of a parametric test, normal distribution is assumed. The strength of the relationship is given by the correlation co-efficient ( $r$ ). A positive correlation means that as one variable increases the value of the other also increases. Conversely, a negative correlation means that as the value of one variable increases, the other decreases. In a perfect correlation,  $r = \pm 1.0$ . No association is indicated by  $r = 0$ . The meaning of the size of the correlation varies between authors but generally,  $r = \pm 0.2-0.4$  is considered a weak correlation,  $r = > \pm 0.4-0.6$  a moderate correlation and  $r = > \pm 0.6-0.8$ , a strong correlation (Coolican, 2009). P values indicate the statistical significance of any relationships. In this analysis, no statistically significant correlations were found between age ( $r = -0.04$ ,  $p = 0.78$ ) or time with illness ( $r = -0.15$ ,  $p = 0.19$ ) and self-care.



In conclusion, no relationships were found between socio-demographic or illness-related characteristics and self-care in this sample which in general, is in contrast to other published studies. The reasons for this are discussed in Chapter seven, however, it is speculated that as the main purpose of the SDQ was to describe the characteristics of the sample, rather than determine relationships between these variables, the study may have not been adequately powered to determine these relationships.

#### **6.4.7 Relationships between illness representations and treatment beliefs**

The CSM assumes that beliefs are not independent but related to each other and organized into clusters (Cameron and Moss-Morris, 2004; Leventhal et al, 1997). For example, the belief that the illness will last a long time is likely to be associated with a belief in more serious consequences and an illness which cannot be cured. In relation to treatment beliefs, concerns may be expected to correlate with the belief that medication use impacts on lifestyle. Illness representations are also expected to be related to treatment beliefs according to Horne (1997), for example, a belief in the necessity of medication may be related to a strong belief that the illness can be controlled by medication.

In order to determine any relationships between beliefs, Pearson's correlation co-efficients ( $r$ ) were calculated and presented in Table 6.16. It can be seen that a large number of statistically significant correlations were found which were moderate ( $r > \pm 0.4 - 0.6$ ) or weak ( $r = \pm 0.2 - 0.4$ ) in strength. Although all statistically significant correlations are presented here, only those correlations described as moderate are discussed, as Harris and Taylor (2008) argue that even very weak correlations can achieve statistical significance in large samples. Therefore, the question arises about whether such weak correlations are meaningful. Those relationships, which are believed to be most important, are discussed further in Chapter seven.

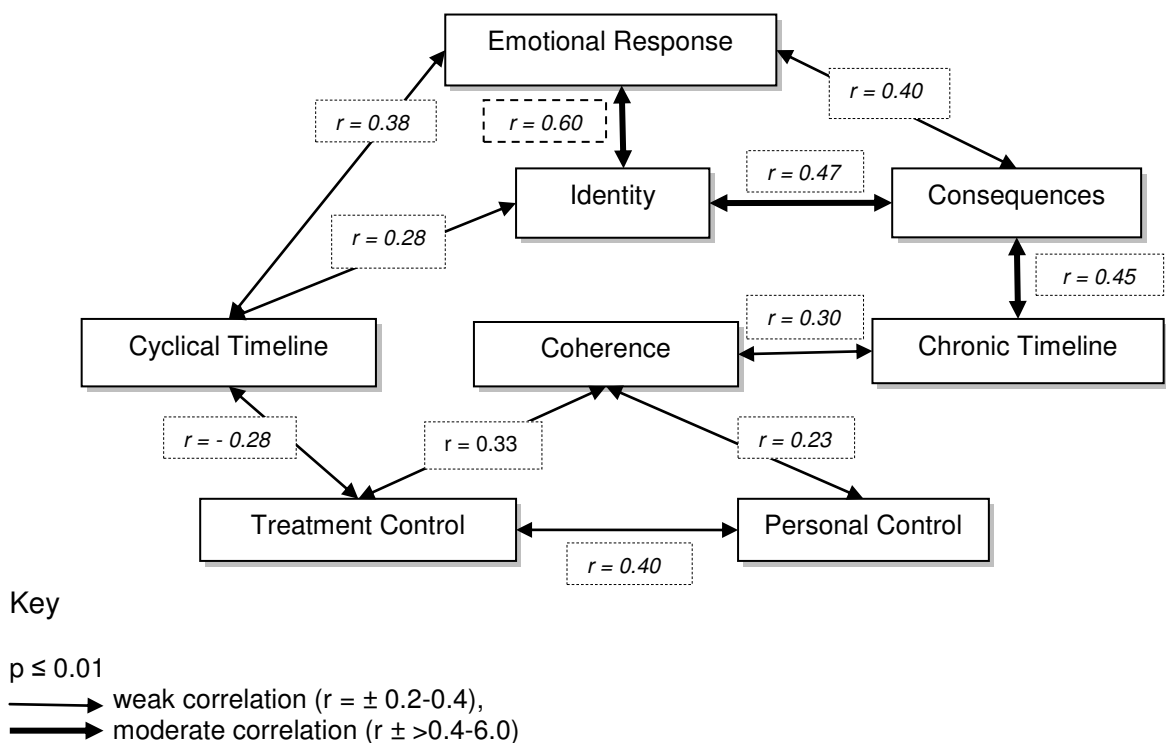
Table 6.16 Correlations Between Illness Representations, Treatment Beliefs and Self-Care

	Identity	Timeline (acute/ chronic)	Con- sequences	Personal control	Treatment control	Timeline (cyclical)	Coherence	Emotional	Necessity	Concerns	Knowledge	Social Influence	Impact on Lifestyle	Self- care
Identity	1													
Timeline (acute/chronic)	0.12	1												
Consequences	<b>0.47**</b>	<b>0.45**</b>	1											
Personal control	-0.19	-0.04	0.03	1										
Treatment control	<b>-0.24*</b>	-0.15	<b>-0.21*</b>	<b>0.40**</b>	1									
Timeline (cyclical)	<b>0.28**</b>	-0.03	0.15	-0.15	<b>-0.28**</b>	1								
Coherence	0.16	<b>0.30**</b>	0.06	<b>0.23**</b>	<b>0.33**</b>	-0.14	1							
Emotional	<b>0.60**</b>	0.09	<b>0.40**</b>	-0.17	<b>-0.20*</b>	<b>0.38**</b>	-0.04	1						
Necessity	<b>0.37**</b>	<b>0.35**</b>	<b>0.28**</b>	0.04	0.04	-0.04	<b>0.24**</b>	<b>0.19*</b>	1					
Concerns	<b>0.32**</b>	0.05	<b>0.31**</b>	<b>-0.28**</b>	<b>-0.29**</b>	<b>0.30**</b>	<b>-0.21*</b>	<b>0.50**</b>	0.09	1				
Knowledge	0.17	<b>0.21*</b>	0.02	<b>0.23**</b>	<b>0.25**</b>	-0.14	<b>0.36**</b>	-0.03	<b>0.34**</b>	<b>-0.33**</b>	1			
Social Influence	<b>0.26*</b>	-0.17	0.03	<b>-0.18*</b>	<b>-0.23**</b>	0.09	-0.16	<b>0.22*</b>	0.02	<b>0.20*</b>	<b>-0.33**</b>	1		
Impact on lifestyle	0.09	0.01	0.15	-0.16	<b>-0.19*</b>	<b>0.32**</b>	-0.01	<b>0.18*</b>	-0.08	<b>0.50**</b>	<b>-0.36**</b>	<b>0.29**</b>	1	
Self-Care	0.17	<b>0.21*</b>	<b>0.25**</b>	0.18	<b>0.27**</b>	<b>-0.22*</b>	<b>0.39**</b>	0.07	<b>0.45**</b>	-0.14	<b>0.51**</b>	<b>-0.23*</b>	<b>-0.39**</b>	1

\*\* Correlation is significant at the 0.01 level (2-tailed). \* Correlation is significant at the 0.05 level (2-tailed)

A number of moderate and weak correlations were found between illness representations, which were statistically significant. The number of symptoms (identity) correlated with a negative emotional response ( $r = 0.60$ ,  $p \leq 0.01$ ). That is, the higher the number of symptoms, the greater the emotional impact, indicating the emotional burden associated with this complex condition. However, it may also suggest that those individuals with depression or anxiety, for example, attribute more symptoms to their illness. Similarly, the number of symptoms correlated with the belief that the illness had serious consequences ( $r = 0.47$ ,  $p \leq 0.01$ ), indicating that the presence of a high number of symptoms which could be attributed to heart failure, resulted in the construction of a serious model of the illness. The belief that the illness had serious consequences was also correlated with a belief that the illness was a chronic or long-term condition ( $r = 0.45$ ,  $p \leq 0.01$ ) again, describing the serious nature of the illness. All correlations are illustrated in Figure. 6.4.

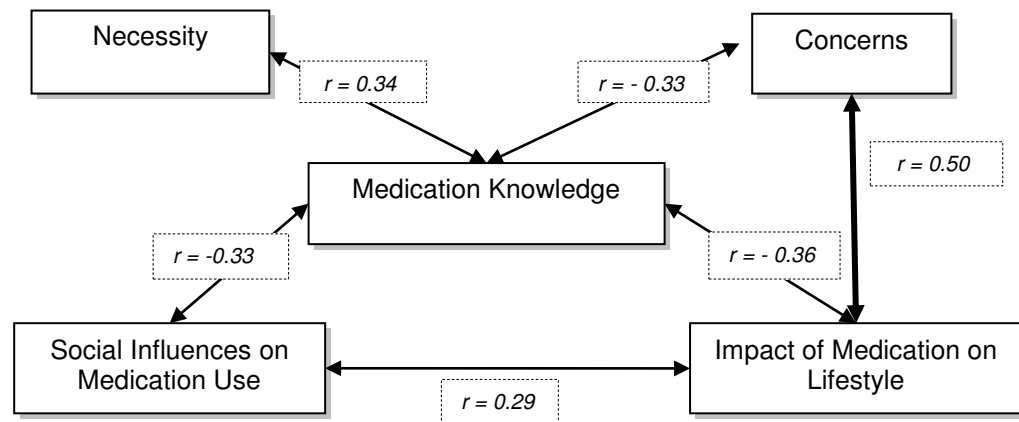
**Figure 6.4 Relationships Between Illness Representations**



As with illness representations, a number of correlations were found between treatment beliefs (Figure 6.5). A moderate correlation was found between concerns about medication and the impact of medication use on lifestyle ( $r = 0.50$ ,  $p \leq 0.01$ ). This is not surprising given

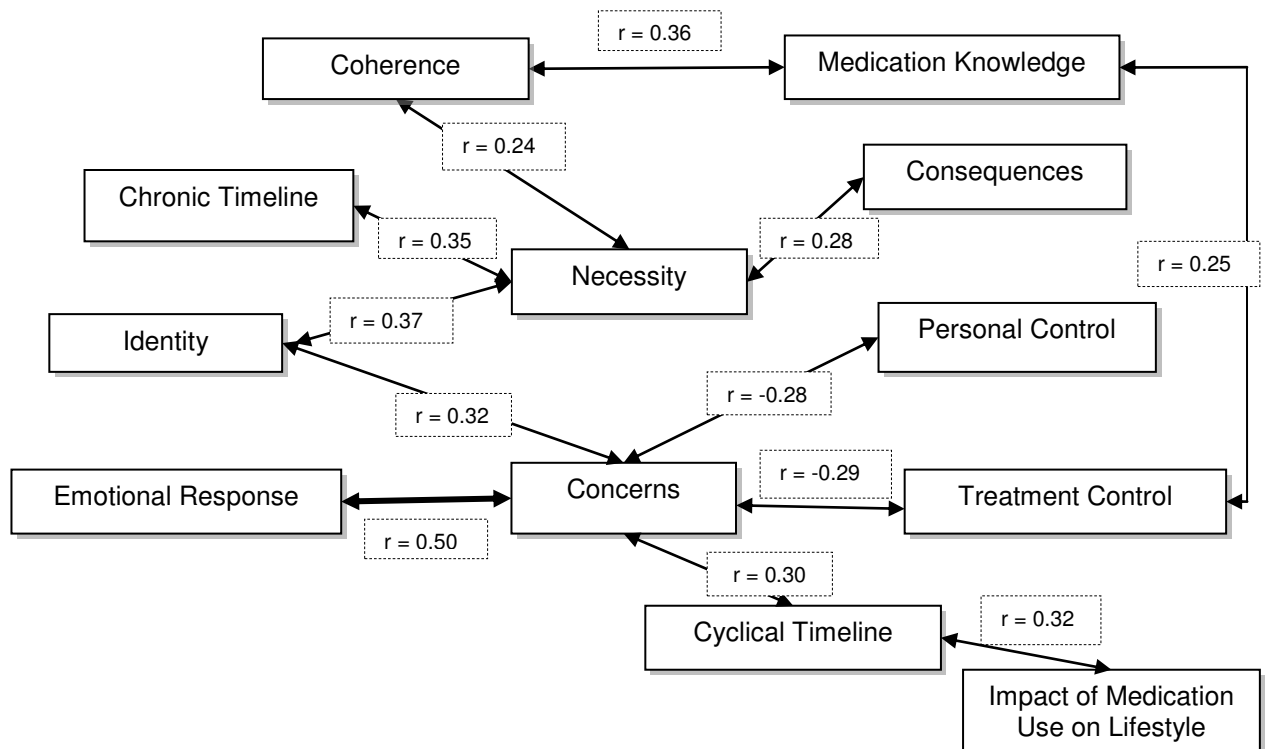
that this domain can be considered a practical, 'real-life' example of concerns, as suggested by the Factor analysis of the MUHFQ with one item cross-loading with these two domains.

**Figure 6.5 Relationships between Treatment Beliefs**



One moderate, positive correlation was found between illness representations and treatment beliefs. A negative emotional response to the illness correlated with concerns about medication ( $r = 0.50$ ,  $p \leq 0.01$ ) indicating that worries about side-effects and drug interactions for example, may result in more general fears and anxieties about the illness or vice versa. All relationships are summarised in Figure 6.6.

**Figure 6.6 Relationships between Illness Representations and Treatment Beliefs**



#### 6.4.8 Relationships between gender and treatment beliefs

From the qualitative data, discussed in Chapter four, it was hypothesised that social influences on medication use were influenced by gender in that men reported greater spousal influences in practical medication management. It was further suggested that this influence had negative implications for perceived medication knowledge. To determine the influence of gender on social influences on medication and medication knowledge, independent t-tests were carried out. An independent t-test assumes that there is no difference between the means of two populations. That is, there is no difference between men and women in relation to social influences on medication use and perceived medication knowledge. The results of this analysis are presented in Table 6.17.

**Table 6.17** Relationships Between Social Influences on Medication Use, Medication Knowledge and Gender

	Number of Participants (n)	Mean	SD (±)	t	df	p
Social Influences on medication use						
Male	111	-2.46	2.50	2.25	151	0.03
Female	42	-3.43	1.99			
Medication Knowledge						
Male	113	3.78	2.14	-0.54	154	0.59
Female	43	3.98	1.80			

Male participants reported greater social influences on medication use (mean = -2.46, range -6 to +6, SD  $\pm$  2.50) than did females (mean = -3.43, range SD  $\pm$  1.99) and this difference was statistically significant ( $t = 2.25$ , 151 df,  $p = 0.03$ ). This supports the findings of the interview data that men may be more reliant on family members, especially spouses for medication management.

However, this did not impact significantly on perceived medication knowledge since, although females reported greater knowledge (mean = 3.98, range -10 to +10, SD  $\pm$  1.83) than men (mean 3.78,  $\pm$ SD, 2.14), this difference was not statistically significant ( $t = -0.54$ , 154 df,  $p = 0.59$ ).

#### 6.4.9 Relationships between illness representations, treatment beliefs and self-care

From the literature and according to the CSM, it was hypothesised that the beliefs that the illness has a chronic timeline, can be controlled and has serious consequences might result

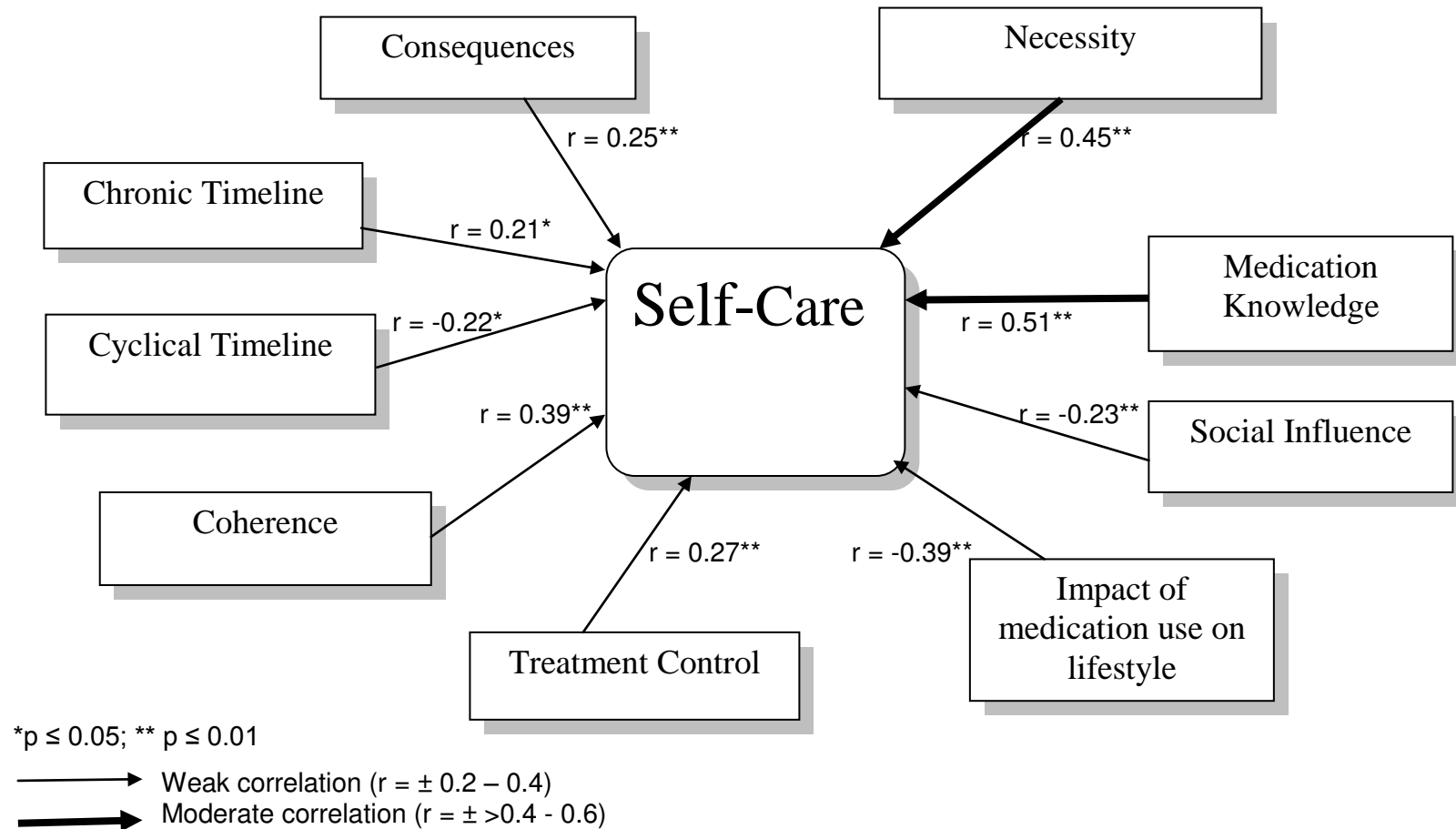
in enhanced self-care in heart failure. A high number of symptoms (identity) may reduce self-care. The specific symptom of daytime sleepiness was predicted to reduce the ability to self-care. Lack of illness coherence and negative emotions such as depression or anxiety may also result in poor self-care.

There is limited published evidence for the influence of treatment beliefs on self-care in heart failure although it is hypothesised, here, that strong necessity beliefs, few concerns, high perceived medication knowledge and limited impact of medication use on lifestyle may be related to enhanced self-care. Social influences on medication use may enhance adherence through practical support in medication management or conversely, may negatively influence self-care when family and friends hold more negative views of medication.

In this analysis, two factors were moderately, positively correlated with self-care: knowledge about medication ( $r = 0.51$ ,  $p \leq 0.01$ ) and a belief in the necessity of medication ( $r = 0.45$ ,  $p \leq 0.01$ ). A number of other weak but statistically significant correlations were noted. All correlations are presented in Figure 6.7. A necessity-concerns differential was calculated (necessity minus concerns) since Horne et al (1999) suggest this may be a better predictor of behaviour than either necessity or concern beliefs alone. The correlation with self-care was  $r = 0.38$  ( $p \leq 0.01$ ), that is, weaker than necessity beliefs alone. From this analysis, treatment beliefs appeared to have greater influence on self-care than illness representations, although illness coherence was the next most strongly correlated belief with self-care ( $r = 0.39$ ,  $p = 0.01$ ).

In relation to specific symptoms, only sexual difficulties was weakly, negatively correlated with self-care ( $r = -0.22$ ,  $p \leq 0.05$ ), that is, the perception that sexual difficulties was a symptom of heart failure was related to poor self-care. Although this weak correlation might have occurred by chance, this is a finding which has not been documented in other studies. There were no significant correlations between beliefs about specific causes of the illness and self-care which is consistent with the finding that participants were unable to identify causative factors. Those relationships which are most strongly correlated with self-care are discussed, in detail, in Chapter seven.

Figure 6.7 Relationships between Illness Representations, Treatment Beliefs and Self-Care



Stepwise multiple regression was used to determine those factors most strongly predictive of self-care. Unlike correlation co-efficients, regression assumes one variable precedes another. In stepwise regression, a list of independent (predictor) variables are entered and the program selects the order in which the variables are added (Pallant, 2010). Before analysis, the adequacy of the sample size was considered. Tabachnick and Fidell (2007) suggest that the sample size should be greater than  $50 + (8 \times \text{the number of predictor variables})$ . In this analysis 9 predictor variables were included, as discussed below. Therefore,  $50 + (8 \times 9) = 122$ , which is within the sample size of 169 in this analysis.

Those illness representations and treatment beliefs which had been found to correlate significantly ( $p < 0.05$ ) with self-care in earlier analysis were included in the regression. First, the illness representations of consequences, coherence, treatment control, timeline (acute/chronic) and timeline (cyclical) were included. This constituted model 1 of the regression. The treatment beliefs of necessity, medication knowledge, social influences on medication use and the impact of medication use on lifestyle were then also added (model 2). Model 2, therefore consisted of both illness representations and treatment beliefs.

From this analysis, illness representations alone (model 1), accounted for 23% of the variance (Adjusted  $R^2 = 0.23$ ,  $F = 6.77$ ,  $p = <0.001$ ). Model 2, the final regression model was highly significant and explained 46% of the variance (Adj.  $R^2 = 0.46$ ,  $F = 9.93$ ,  $p = <0.001$ ) (Table 6.18).

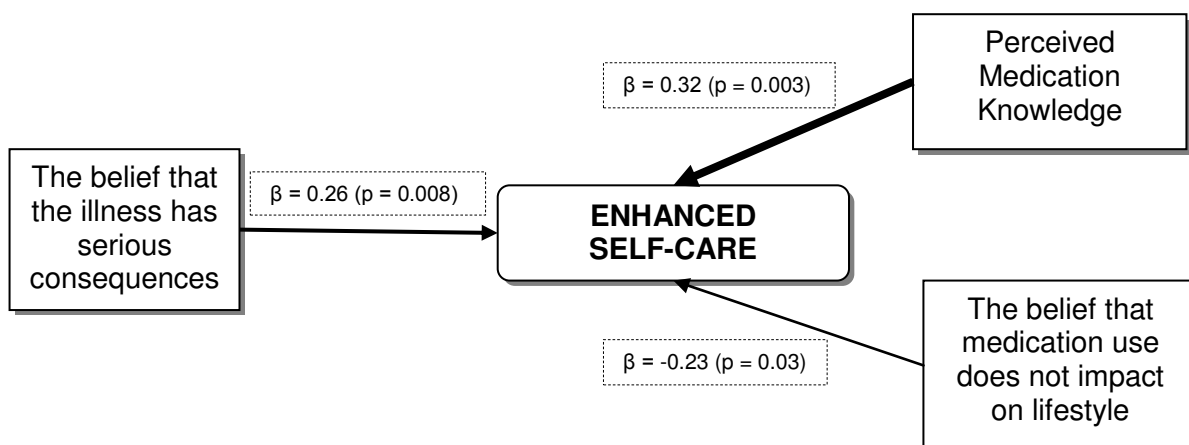
**Table 6.18**      **Regression Analysis of Factors Predictive of Self-Care**

<b>Model</b>	<b>R</b>	<b>R Square</b>	<b>Adjusted R Square</b>	<b>F</b>	<b>p</b>
1	0.52	0.27	0.23	6.77	<0.001
2	0.71	0.51	0.46	9.93	<0.001

The standardised coefficients (Beta) showed that three of the variables were also significant. These were perceived medication knowledge ( $\beta = 0.319$ ,  $p = 0.003$ ), the belief in the illness having serious consequences ( $\beta = 0.258$ ,  $p = 0.008$ ) and the impact of medication use on lifestyle ( $\beta = -0.231$ ,  $p = 0.03$ ) (Figure 6.8).



**Figure 6.8** Beliefs Predictive of Self-Care



This analysis demonstrates that both illness representations and treatment beliefs are significant predictors of self-care, which confirms the main hypothesis of the study. In particular, self-care is enhanced when perceived knowledge about medication is high, when there is a belief that heart failure has serious consequences and when there is minimal impact of medication use on lifestyle. The implications of these findings are discussed in Chapter seven.

## 6.5 CONCLUSION

In conclusion, this chapter has considered the methods and results of phase two, the main survey. 169 sets of questionnaires were completed, representing a response rate of 50.4%, suggesting the study was sufficiently powered to achieve statistically significant results. The questionnaires were examined for internal consistency using Cronbach's alpha ( $\alpha$ ). In the IPQ-R (HF), all domains demonstrated satisfactory reliability. In the MUHFQ, again all domains demonstrated satisfactory reliability, although it should be noted that the impact of medication use on lifestyle domain demonstrated only moderate reliability of  $\alpha = 0.56$ . Factor analysis supported the proposed 5-factor structure of the MUHFQ. In the LAYHFQ, internal consistency was demonstrated for the questionnaire as a whole but not for a number of individual domains, with lifestyle adherence ( $\alpha = 0.13$ ) and managing symptoms and the emotional and social consequences of the illness ( $\alpha = 0.48$ ), demonstrating unsatisfactory internal consistency. Factor analysis also failed to support the proposed 5-factor structure. The overall reliability and validity of the questionnaires is discussed further in Chapter seven.

The socio-demographic and illness-related characteristics of the sample have been described. The extent to which the sample is representative of the heart failure population is considered in the following chapter.

Illness representations, treatment beliefs and self-care have been described, which addresses the first aim of the study which was to explore these beliefs and behaviours in this population. In summary, a high number of symptoms were reported with the illness being described as a chronic or long-term condition, with serious consequences. A high degree of both personal and treatment control was described with participants agreeing that the illness 'made sense' to them. However, participants were largely unable to positively identify the cause of their heart failure with only ageing and stress or worry identified as a likely causes. Participants did not report negative emotions, such as depression or anxiety, as a result of the illness. A strong belief in the necessity of medication was described with few concerns. Social influences on medication use and the impact of medication use on lifestyle were also infrequently described. Total self-care was reportedly high for all behaviours, with the exception of taking regular exercise. Non-adherence to medication, both intentional and unintentional was infrequently described.

A number of moderate, positive correlations between beliefs were found, namely, the perceived number of symptoms and a negative emotional response; the number of symptoms and the belief that the illness has serious consequences; a chronic timeline and the belief that the illness has serious consequences; a negative emotional response to the illness and concerns about medication and finally, the belief that medication use impacted on lifestyle correlated with concerns about medication. In relation to self-care, a belief in the necessity of medication and perceived medication knowledge were most strongly correlated with self-care. A number of other weak, but statistically significant correlations were found, most notably the symptom of sexual difficulties was related to poor self. No relationships were found between socio-demographic and illness-related factors and self-care, although men reported greater social influences on medication use, compared to women.

Using multiple regression, illness representations and treatment beliefs were both significantly predictive of self-care. Of greatest significance were perceived medication knowledge, the belief that heart failure had serious consequences and the impact of medication use on lifestyle. The following chapter discusses these findings in relation to the literature, the CSM and the interview findings and considers the implications for practice.

## **CHAPTER SEVEN: DISCUSSION OF RESULTS AND CRITIQUE OF THE METHODOLOGY**

The purpose of this chapter is to discuss the results of the study in relation to the literature and the aims of the research and to critique the methodology and methods employed. In summary, the aims of the research were to explore illness representations, treatment beliefs and self-care in heart failure and to determine any relationships between these beliefs and behaviour. In relation to the methodology, the strengths and limitations of the mixed method research design, sampling strategies, data collection and methods of analysis are discussed. A judgement is made on the reliability and validity of the questionnaires and suggestions are given for their further development. The use of the theoretical framework (the CSM) and the concept of self-care according to Dickson et al (2006) are also considered. Finally, the implications for nursing and healthcare practice and opportunities for future research are discussed.

### **7.1 ILLNESS REPRESENTATIONS, TREATMENT BELIEFS AND SELF-CARE**

#### **7.1.1 Illness representations**

Participants reported an average of over nine symptoms believed to be due to heart failure. This is consistent with the qualitative findings and characteristic of the nature of the condition which affects almost all body systems. Such diverse and debilitating symptoms impact on the patient and their families in many areas of daily living such as physical activity and emotional and social well-being. Cherrington et al (2006), using the IPQ-R, found an average of 6.6 symptoms which patients believed were related to their heart failure, although as the IPQ-R was not adapted for use in heart failure the number of symptoms reported here may be an underestimate. Similarly, Morgan (2008) using the IPQ-R, concluded that patients with heart failure experience fewer symptoms than those with other long-term conditions. Again, that the identity scale in this study was not specific to heart failure, may explain this lower score.

Breathlessness and fatigue were the most prevalent symptoms reported although daytime sleepiness, loss of strength, swollen ankles, dizziness, sleep difficulties, wheeziness, weight gain and sexual difficulties were reported by over half of the respondents. This is consistent with the findings of Morgan (2008) who, using the IPQ-R, found that loss of strength, breathlessness and fatigue were the most commonly reported symptoms.

All of these are recognised symptoms of heart failure (Ahmed et al, 2004; Fonseca et al, 2004; Badgett et al, 1997; Davie et al, 1996; Harlan, 1977) and, with the exception of swollen ankles, were also described by the interview participants. Interestingly, the high

prevalence of sexual difficulties in the survey might suggest under-reporting of this potentially sensitive symptom by the interview sample. It is important, therefore, that healthcare professionals actively seek to assess the presence of this symptom and its impact on the individual and their partners as patients may be reluctant to bring this subject up themselves during a clinical consultation.

Chest pain and palpitations are generally considered to be symptoms of CHD and cardiac arrhythmias but were commonly identified as symptoms of heart failure by the survey participants. This suggests a high incidence of cardiac co-morbidities and perhaps more importantly, a limited ability to differentiate between the symptoms of heart failure and other cardiac conditions. A high incidence of cardiac co-morbidities is reported by Thomas and Valezquez (2005) and Cowie et al (1999) who found that CHD is three times more common in those with heart failure than in the wider population with atrial fibrillation (AF) found in 30% of patients. In this sample it was not possible to confirm the presence of co-morbidities without access to medical notes. Since many participants described symptoms of CHD and arrhythmias but did not list these conditions as co-morbidities, a lack of a clear illness identity is suggested. This is supported by the qualitative data where some participants were unable to differentiate symptoms of their illness from other co-morbidities, particularly those of a cardiac nature, the effects of medication or an emotional response such as panic attacks.

According to the CSM, identity not only relates to the symptoms associated with the illness but also to the illness diagnosis or label. From the interview data, most participants were unable to clearly relate the label 'heart failure' to their understanding of their symptoms or were confused by a number of complex labels. This unclear illness identity is also suggested by Horowitz et al (2004) who describe few patients labelling their illness as heart failure and an inability to isolate symptoms of heart failure from other conditions. Since there are significant differences in the aetiology, symptoms and management of different cardiac conditions, this lack of a clear illness identity may lead to the development of misconceptions about heart failure and its treatment, which may result in disagreement or conflict between patients and healthcare professionals (Kleinman, 1988).

In relation to causal representations, there was a general lack of agreement that the illness was caused by the factors listed in the IPQ-R (HF). Only ageing and stress or worry were positively identified as causes with only ageing statistically significant. This supports the assertion by Bauman et al (1989) and Leventhal et al (1997) that individuals seek to determine if symptoms or functional changes reflect a disease process or can be attributed to age or stress – the so-called 'age-illness' and 'stress-illness' rules. It seems

that, perhaps due to the presence of some relatively non-specific symptoms such as fatigue and loss of strength, and the disease trajectory, heart failure can reasonably be attributed to advancing age. According to Leventhal et al (1997), stress is a widely accepted cause of disease amongst patients and ambiguous or non-specific symptoms in the presence of life stress are readily associated, as found in both the survey and interview data in this study. Stress as a cause of heart failure was also cited in the study by Horowitz et al (2004). In contrast, Morgan (2008), using the IPQ-R, found that the belief that the illness was hereditary was identified as the most likely causative factor, although stress and worry and ageing were the next most frequently cited causes.

The DH (2003) suggests that most cases of heart failure in the UK are caused by CHD. In this study, the inability of patients to differentiate CHD from heart failure, meant, unsurprisingly, that they also failed to recognise CHD as a potential cause of their illness, as indicated by the lack of agreement that the illness was caused by '*A previous heart attack*'. Similarly, in the interview sample, CHD was not identified as a causative factor.

The overall lack of agreement that the illness was caused by the suggested factors might indicate that some items were missing from the IPQ-R (HF). All causes identified by the interview participants were included in the scale, as well as those commonly recognised from a medical perspective or identified in other published studies. The IPQ-R (HF) also included an open question giving the opportunity for participants to identify any factors which were not listed. From this analysis, only two further causative factors were identified - pregnancy and loneliness, each of which was cited only once. It seems unlikely, then, that any important causative factors were omitted in the IPQ-R (HF). The inability of heart failure patients to identify causal factors was also found by Cherrington et al (2006) using the IPQ-R and Horowitz et al (2004). It is apparent, therefore, that there is a difference between the biomedical view of heart failure, which is caused primarily by existing CHD, and the patient perspective where advancing age and stress or worry are seen as the most likely causes. However, in general, the cause of the illness largely remains a mystery for most patients.

In relation to timeline, there was a strong belief that heart failure was a chronic illness which, given that the average time with the illness was 7.34 years, is perhaps unsurprising. The belief that heart failure is a long-term condition represents an accurate understanding of the nature of the illness according to a biomedical model and is consistent with the qualitative findings and those of Morgan (2008), Cherrington et al (2006) and Voelmeck (2006). In contrast, Horowitz et al (2004) found a belief in an acute timeline with participants not recognising that their illness deteriorated over time.

The illness was not generally seen as cyclical although some interview participants described 'good days and bad days' in relation to worsening symptoms or negative emotions. That symptoms did not entirely disappear might explain the lack of agreement with a cyclical timeline. This represents an accurate and realistic view of the nature of the illness. In contrast, Cherrington et al (2006) concluded that heart failure was perceived to be cyclical in nature. However, it should be remembered that this study included a very small sample ( $n = 22$ ), a point acknowledged by the authors.

The illness was perceived to have serious consequences which is supported by the qualitative findings and consistent with the findings of Cherrington et al (2006) and Voelmeck (2006). The interview findings here, revealed that the nature of these consequences was largely physical and social. Although negative emotions were described, these were categorised as an emotional response rather than consequences, according to the CSM. In terms of physical consequences, poor exercise tolerance due to symptoms of breathlessness and fatigue were described with a resulting inability to carry out household chores. Mahoney (2001) also identified physical disruption as a significant consequence of the illness. Similarly, Jeon et al (2010) in a systematic review of the literature found that physical restrictions due to breathlessness and fatigue were commonly identified in qualitative studies. Withdrawal from social situations and subsequent social isolation was described by the interview participants. Mahoney (2001) and Jeon et al (2010) similarly describe a reliance on close family members but disengagement from wider social networks. The implications of living with heart failure for the individual and their family and friends can therefore be wide-ranging and disabling, affecting many aspects of life.

There was a strong belief in both personal and treatment control in this study, as also described by Morgan (2008), Cherrington et al (2006) and Voelmeck (2006). Although a belief in medication controlling the illness and its symptoms was described in the interview data, personal control was less well articulated with few participants describing a high degree of control over the illness. Rather, personal control was described in terms of maintaining a positive attitude which suggests a strategy for controlling negative emotions rather than the illness itself. It may be that the belief in personal control describes strategies to control negative emotions rather than symptoms or the illness itself, which is best controlled by medication. This may explain the contrasting findings of Albert and Zellar (2007) who, using the SIBHFT, found patients had little perceived control over their symptoms, and Horowitz et al (2004) who also concluded that participants had little personal control as demonstrated by an inability to prevent exacerbation of symptoms.

There was a high level of reported illness coherence which was also found by Cherrington et al (2006), using the IPQ-R. However, when data are collected by qualitative methods, the opposite conclusion seems to be reached. From the interview data, although most participants agreed that their illness made sense to them, this was frequently not demonstrated in other responses. For example, a lack of illness coherence was demonstrated through an inability to identify the cause of the illness and a lack of a clear illness identity. Other qualitative studies (Horowitz et al, 2004 and Mahoney, 2001) similarly report a lack of illness coherence. It may be that two subtly different concepts of coherence are being described – the *belief* that the illness makes sense and *demonstrable* illness coherence. The belief that the illness makes sense, as measured by the IPQ-R, seems to be more related to self-efficacy beliefs (Bandura, 1977) or the confidence in one's ability to understand the illness through agreement with statements such as '*I have a clear picture or understanding of my illness*'. Illness coherence may also be demonstrated through the accuracy of beliefs linked to behaviour. Horowitz et al (2004) describe participants not recognising heart failure as a chronic illness and not being able to minimise fluid-build up through specific self-management behaviours as an illustration of a lack of illness coherence. This may explain the different findings according to the methodology used, where a coherent picture of the illness is reported in quantitative studies using the IPQ-R, but in qualitative studies there is a lack of demonstrable coherence. It may be important, therefore, to know how illness coherence is defined and measured in published studies. Perhaps more importantly, the relationship between the different definitions of coherence and self-care behaviour should be examined as different interventions may be needed to promote self-efficacy beliefs or correct misconceptions.

In relation to the emotional response to the illness, few negative emotions were reported in the survey, although this was not statistically significant. Morgan (2008) and Cherrington et al (2006) similarly reported neutral feelings about the illness. The survey findings are in contrast to the interview data where negative emotions such as depression, anxiety, panic, loss of confidence, anger, frustration and guilt were widely reported. Strong negative emotions were also found in qualitative studies by Jeon et al (2010), Horowitz et al (2004), Zambroski (2003) and Mahoney (2001). The reasons for these different findings are speculative but may reflect a degree of self-selection by the interview participants in that those experiencing negative emotions perceived some benefit in talking about their illness and so were more likely to agree to take part in the interview. Alternatively, it is possible that talking about the experience of living with heart failure in an in-depth interview may have facilitated the expression of more negative emotions. It might be that uncovering deep, personal emotions is more likely when individuals are given time to

express how they feel in a safe environment in the presence of a sympathetic, active listener.

It is difficult, therefore, to accurately determine the extent of the emotional response to the illness as it seems to be dependent on the methodology, to some extent. However, what is clear is that a wide range of emotions may be experienced with some patients experiencing severe emotional distress. Depression has been widely cited in the literature either as a symptom, a co-morbidity or an emotional response (Holzapfel et al, 2009; Riegel et al, 2007b; Dickson et al, 2006; Lesman-Leegte et al, 2006; Leventhal et al, 2005 and Cowie et al, 1999). Other emotions such as anxiety and panic may be highly disabling with significant social consequences, as described by some interview participants.

In conclusion, from an integrated discussion of the qualitative and quantitative findings, participants attributed a high number of symptoms to heart failure which represents a significant symptom burden. Those symptoms identified were largely consistent with the medically defined disease. Sexual difficulties may be being under-reported with patients finding it difficult to talk about this sensitive issue. This has implications for practice in that open discussion may need to be facilitated by healthcare professionals.

There was a lack of a clear illness identity, particularly in relation to other cardiac illnesses, with individuals unable to clearly differentiate between CHD, arrhythmias and heart failure in terms of diagnosis, symptoms and causative factors. In addition, other co-morbidities, the effects of medication and emotional responses, especially panic attacks, made the identification of the illness difficult. There was a lack of certainty in relation to the cause of the illness with advancing age and stress or worry seen as the most likely causative agents. This is in keeping with other long-term conditions and articulated by the age-illness and stress-illness rules (Leventhal et al, 1997).

The illness was believed to be chronic in nature with serious consequences which is consistent with the medically defined view of heart failure. Consequences were physical, social and psychological in nature, reflecting a significant impact on the lives of patients and their families. A high degree of both personal and treatment control was reported although personal control was less clearly described in the interview sample where it was described in terms of controlling negative emotions rather than physical symptoms. Survey participants described a high degree of illness coherence although this was not generally demonstrated in the interview sample or reported in other qualitative studies. It is suggested that illness coherence may be described as a self-efficacy belief or demonstrated through the relationships between illness representations and behaviour.



Few negative emotions were reported by the participants in the survey which may reflect the methodology used either due to selection bias in the interview sample or the increased likelihood of deep emotions being expressed in a qualitative interview. This is supported by published literature where negative emotions are vividly described in qualitative studies but few negative emotions are reported in questionnaire surveys. As such, the prevalence of negative emotions, such as depression or anxiety in heart failure, may be difficult to determine. However, what is clear is that the emotional impact of the illness can be severe and debilitating for some patients.

### **7.1.2 Treatment beliefs**

From the interview data, five domains of treatment beliefs were identified. Necessity and concern beliefs, as described by Horne et al (1999) in the BMQ, and three additional domains relating to perceived knowledge about medication, social influences on medication use and the impact of medication use on lifestyle.

In relation to necessity beliefs, there was a strong belief in the necessity of medication. This is supported by the interview data where there was a perception that symptoms improved as a result of taking medication. Although few studies have addressed treatment beliefs in heart failure, Ekman et al (2006) found that 82% of patients believed that taking medication would make them feel better, which also suggests strong necessity beliefs.

However, these beliefs were also accompanied by some concerns about medication. In the interview data, concerns appeared to be more widespread than in the survey, suggesting that the interview participants either held a more negative view of their medication or were more likely to express concerns in an interview. This is consistent with the discussion above, relating to the prevalence of negative emotions, in that a more negative view of the illness and its treatment was expressed in the qualitative interviews.

Concerns assessed in the survey included general worries about medication and fears about side-effects, drug interactions and dependency. Drug dependency was not identified as a concern in the interview sample and is not generally seen as an issue related to heart failure medication by healthcare professionals. However, this item was included due to the decision to retain the BMQ intact. The nature of concerns, in the interview sample, focused on perceived medication side-effects and drug interactions with other prescribed medication and medications bought 'over the counter'. Concerns about the side-effects of heart failure medication were also found by Riegel and Carlson (2002), Rogers et al (2002) and Stromberg et al (1999). In the interview sample, these concerns were enhanced by reading the patient information leaflets contained within the medication boxes, a finding echoed by Rogers et al (2002). Higher doses also seemed to be related

to more concerns in the interview sample. The practice of up-titration of many heart failure drugs, described by NICE (2010) as a 'start low, go slow' approach to medication management, may mean that negative effects were more likely to be associated with an increased dose. Psychological support and education about the effects of medication would, therefore, seem to be especially important during the process of up-titration.

Perceived knowledge about medication including drug actions, names, doses and timing of administration was reportedly good. It is important to emphasise, however, that the accuracy of this knowledge was not assessed in the questionnaire which would have required cross-checking with medication prescriptions, for example. Medication knowledge as assessed here, has more to do with confidence in one's ability to understand the use of medication, and so may be related to self-efficacy beliefs. Perceived medication knowledge has not been assessed in published studies although Ekman et al (2006) found that 69% of heart failure patients were knowledgeable about the names of medication. It is likely that a relationship exists between the accuracy of medication knowledge and self-efficacy beliefs relating to that knowledge, although this requires further investigation.

From the survey data, few social influences in terms of practical help with medication management or the beliefs of others were reported. Although, therefore, not a widespread influence, the interview findings highlighted a group of patients who were dependent on others, particularly wives, for medication management. This hypothesis was tested in the quantitative survey where men reported significantly more social influences on medication use than women. This supports the view that the management of the illness can be a shared responsibility between husband and wife and highlights the reliance some men with heart failure have on their partners in order to take their medication appropriately. This has implications for clinical practice in that the loss of that partner, which might be expected in older age groups, may make patients particularly vulnerable to unintentional, non-adherence as a result of a reduced ability to take medication as prescribed. Additional support from other family members, pharmacists and healthcare professionals may, therefore, be essential.

A limited impact of medication use on lifestyle was reported in the survey, however, since the internal consistency of this domain was only moderate at  $\alpha = 0.56$ , this result should be interpreted cautiously. Although related to concerns about medication, this specific, negative effect of medication use was reported by some participants in the interview sample. Impact on lifestyle primarily related to difficulties in the ability to take medication when going out, disruption to sleep and social activities due to the effects of diuretics and

the need to frequently monitor the effects of medication, through clinic appointments and blood tests. Mahoney (2001) also described the experience of living with heart failure as a disruption to daily life, although this was not explicitly related to the use of medication. Glaser and Strauss (1967) recognised the work involved in living with long-term conditions which can be seen in the effort involved in taking medication frequently and monitoring the effects, both of which require adjustments to lifestyle. Although managing the effects of diuretics is recognised as disruptive for patients (Nicholson, 2007), no studies have been found which address other implications of heart failure medication use on lifestyle. Some aspects of the impact of medication are, however, described in HRQoL studies, for example Dunderdale et al (2008). It may be that some overlap exists between the social and emotional impact of medication use and HRQoL.

In summary, there was a strong belief in the necessity of medication with few concerns apparent in the larger sample. Where concerns were described, these were mostly related to side-effects, especially at higher doses and enhanced by patient information leaflets. Perceived medication knowledge was reportedly high, although it is acknowledged that the accuracy of knowledge has not been measured. Although social influences on medication use were modest, gender differences were apparent with men being particularly reliant on family members. Similarly, the impact of medication use on lifestyle was reportedly low, although the need to take medication frequently, the effects of diuretics and regular monitoring of the illness and the effects of medication, may be particularly problematic for some patients. Overall, this represents a generally positive view of medication but one which is balanced against specific medication concerns and difficulties in managing the medication regime for some patients. In terms of professional practice, the recognition of the burden of the use of medication in heart failure should not be underestimated.

### **7.1.3 Self-care**

Adherence to recommended lifestyle behaviours and medication, monitoring symptoms, managing symptoms and the social and emotional effects of the illness and reporting and seeking help, were themes derived from the literature and the qualitative data. However, with the exception of monitoring symptoms ( $\alpha = 0.70$ ), internal consistency of these domains was not established in the LAYHFQ and Factor analysis failed to support the existence of these theoretical divisions. Despite the lack of support for these self-care domains, individual behaviours could be analysed for frequencies. Total self-care scores were used in determining relationships between beliefs and self-care.

From the survey data, total self-care was high which is consistent with that described by the interview participants. This high score may reflect the fact that the population was drawn from a service with specialist HFN input where participants might reasonably be expected to have had greater educational input and enhanced support for self-care. Social desirability may also be operating with participants wanting to present themselves in a positive light by agreeing with recommended behaviours.

Adherence to all recommended lifestyle behaviours was reportedly high. Those behaviours for which there was with the highest agreement were not smoking and drinking alcohol within government recommended limits. Those behaviours with lowest reported adherence were restricting fluid intake and taking regular exercise, although this was not statistically significant.

Not smoking and drinking alcohol within recommended limits might be considered behaviours recommended as part of a general healthy lifestyle and not necessarily illness-related. This is consistent with the interview findings where healthy lifestyle behaviours were reported but not those specifically related to heart failure. Restricting fluid intake, which is perhaps the most illness-specific behaviour, was less frequently reported. Van de Wal and Jaarsma (2007) also found that adherence to a fluid restriction was infrequently practiced. This finding seems to support the suggested lack of a clear illness identity and coherence in that, whilst those behaviours considered part of the overall public health agenda, hence, applicable to the whole population are practised, those behaviours specific to heart failure, such as restricting fluid, lack meaning and so are infrequently practiced. Taking regular exercise was not generally reported by either the interview or survey sample and might be expected given the age of the population, the presence of co-morbidities and the symptom of reduced exercise tolerance, resulting in a limited ability to exercise. Similarly, taking regular exercise was reported by just 27% of patients in the study by Morgan (2008).

Adherence to medication was high with limited non-adherence reported. This result is consistent with that described in the qualitative sample and findings by Morgan (2008), who, using the EHFSBS, found that adherence to medication was reported by 94% of participants. Other self-report measures of medication adherence (Ekman et al, 2006; Van de Wal et al, 2004 and Granger et al, 2005) also found high adherence to medication. However, it has been suggested by some authors that different levels of adherence may apply to different medications. For example, Albert (2008) found that adherence to ACEI was only 39%. From the qualitative data, some participants reported omitted specific tablets due to concerns about side-effects (aspirin) or the belief that they were no longer

necessary (statins). Hence, an overall estimate of medication adherence may mask individual levels of adherence for different medications.

Intentional non-adherence by omitting tablets or changing doses was infrequently reported in this sample. Again, this is consistent with the interview sample where this was described by only a minority of participants. Changing the time at which medication was taken was more frequently reported and described in both samples. However, this may not be an intentional act of non-adherence but a way of managing medication according to lifestyle such as taking medication after returning home from shopping, for example. HFNs often advocate this practice so this finding perhaps should be viewed as a strategy for maintaining adherence rather than an act of intentional non-adherence.

Unintentional non-adherence through forgetfulness was more frequently reported. Forgetting to take tablets was also described by some interview participants although the fact that this happened on rare occasions was stressed. Dosette® Boxes were used as a strategy to aid memory and manage the medication regime, promoting adherence. However, cognitive deficits, common in heart failure and advancing age may put patients at greater risk of unintentional non-adherence through forgetfulness.

Monitoring deteriorating symptoms such as signs of fluid overload, particularly changes in breathing and the development of a cough were commonly cited. Less specific changes including changes in sleep pattern were less well recognised. Monitoring the effects of medication was the least commonly practised monitoring behaviour. This may be because some patients find it difficult to differentiate between symptoms of heart failure and the effects of medication, as reported by some participants in the interview sample, as well as the belief that monitoring the effects of medication is the responsibility of the doctor or nurse. The practice of regular weighing was reported but less frequently than some other behaviours. This is higher than that reported by either Morgan (2008) or Van de Wal et al (2004) who found that weighing at least once a week was only carried out by 14% and 52% of patients respectively. Again, the rationale for regular weighing is likely to be dependent on a having a clear understanding the nature of the condition, or the illness identity, which may be lacking, as previously discussed.

In contrast to the survey data, the interview findings suggested an overall lack of symptom monitoring. It may be that 'recognising' changes, as defined in the LAYHFQ is a different concept from actively monitoring symptoms as discussed in the interviews and the intended interpretation of this self-care behaviour. In the interview sample, monitoring the illness and the effects of medication was seen as the responsibility of health professionals. This might explain why, on discussion of the questionnaires with the clinic

patients, the term 'checking' for signs of deterioration, as in the pilot version of the LAYHFQ, were not recognisable to patients, prompting a change in terminology. Although further exploration of the concept of symptom monitoring in heart failure is, therefore, advocated, it is suggested that active monitoring of symptoms and the effects of medication may be less commonly practiced than other aspects of self-care.

In terms of managing symptoms and the social and emotional effects of the illness, resting when needed was a commonly reported behaviour. Maintaining a positive outlook was also seen as important. Making an effort to see friends and family and going out as much as possible were also cited. Participants agreed that they were not as active as they could be, although, on reflection, the meaning of this question is ambiguous in that it may describe reduced exercise tolerance which is a common symptom of heart failure, rather than the intended interpretation which was to assess the degree to which participants made an effort to keep active. Furthermore, reversing this question may have made it more difficult to understand. The concept of managing symptoms and carrying out behaviours aimed at maintaining emotional and social well-being, as described here, was largely developed from the qualitative data and is consistent with the CSM and the DH (2006a) vision of self-care. That these behaviours are also prevalent in the survey data suggests this is an important, yet sometimes overlooked aspect of self-care and may reflect strategies to maintain or enhance HRQoL.

Finally, in terms of reporting and seeking help, seeking advice in response to questions or concerns was the most prevalent help-seeking behaviour. Other behaviours such as checking before taking other medication and reporting the effects of medication were less commonly practised, although still highly scored. Reporting any changes to health was least specific to heart failure and so perhaps least relevant in this population. It might also reflect the desire not to be seen as a 'nuisance' to health professionals in reporting insignificant changes to health, which was a concern of some interview patients.

Overall, these findings describe a reliance on health professionals by heart failure patients, especially in terms of managing the emotional effects of the illness by seeking reassurance when worried or concerned. This is reflected in the CSM in that this help-seeking behaviour can be viewed as a coping strategy to manage the emotional effects of the illness. The need for a trusting relationship between the patient and the nurse, GP or pharmacist is implicit in this behaviour. Such a relationship is described as necessary for effective self-care by Sabate (2003) for the WHO.

In summary, adherence to recommended lifestyle behaviours, especially those which can be considered part of a healthy lifestyle was reportedly, commonly practiced. The

behaviour considered most specific to heart failure, namely, restricting fluids was less commonly reported, perhaps reflecting a lack of illness coherence. Medication adherence was reportedly high with intentional non-adherence such as omitting tablets or changing doses, infrequently reported. Unintentional non-adherence through forgetfulness was more frequently reported which may reflect a degree of cognitive impairment due to the condition or advancing age in some patients. Recognising changing symptoms was reported but recognising the effects of medication was the least frequently described monitoring behaviour. This may reflect an inability of some patients to differentiate between symptoms and medication effects, as suggested by the qualitative data. Managing symptoms, specially resting when needed and managing the emotional and social effects of the illness, a theme derived from the qualitative data, was reported which reflects a vision of self-care according to the DH (2006a). Reporting and help-seeking behaviours were highly scored, especially the need to seek reassurance if worried or concerned, again suggesting a powerful need to manage the emotional effects of the illness.

## **7.2 RELATIONSHIPS BETWEEN ILLNESS REPRESENTATIONS, TREATMENT BELIEFS, SOCIO-DEMOGRAPHIC FACTORS AND SELF-CARE**

According to the CSM, illness representations are not independent but related to each other or organised into clusters (Cameron and Moss-Morris, 2004; Leventhal et al, 1997). In addition, illness representations are expected to be related to treatment beliefs (Horne, 1997). In this section, firstly the relationships between beliefs are discussed. As only a small number of studies have considered illness representations in heart failure and almost none have considered treatment beliefs, few comparisons with published literature can be made. Most importantly, the CSM also predicts that beliefs influence behavioural outcomes. This addresses the main aim of the research, which was to determine relationships between illness representations, treatment beliefs and self-care in heart failure.

### **7.2.1 Relationships between beliefs**

Relationships between individual illness representations and treatment beliefs are first discussed, followed by a discussion of the relationships between these two sets of beliefs. Relationships were determined using Pearson's Correlation Co-efficients ( $r$ ).

A number of moderate and weak correlations were found which were statistically significant. These are shown in Table 6.16 and Figure 6.4. However, Harris and Taylor (2008) caution that, in large samples, even small, unimportant correlations may be highly

statistically significant. Therefore, in general, weak correlations ( $r \leq 0.4$ ) are not discussed except where they seem to represent an original or important finding.

The number of symptoms (identity) was positively correlated with a number of other representations but was most strongly related with a negative emotional response to the illness. This means that the greatest emotional impact was felt by those with the highest number of perceived symptoms. From the interview data, for some participants, depression, anger and frustration resulted from an inability to carry out the activities that were important to them due to the presence of physically debilitating symptoms, particularly breathlessness and tiredness, illustrating this relationship between symptoms and negative emotions. However, it could also be the case that participants experiencing negative emotions, such as anxiety or depression, might attribute more symptoms to heart failure. Unlike the IPQ-R (Moss-Morris et al, 2002), the IPQ-R (HF) was unable to distinguish between a general somatic effect of negative emotions and specific perceptions regarding the illness identity due to the need to simplify the identity sub-scale for a heart failure population. A moderate, positive correlation was found between the number of symptoms and the belief that the illness had serious consequences. It seems that the presence of many symptoms, especially those as diverse and debilitating as breathlessness, daytime sleepiness and ankle swelling, for example, leads to the development of the belief that heart failure is an illness with serious consequences.

A positive correlation was also found between a negative emotional response to the illness and the belief in the illness having serious consequences. Hallas et al (2010) also found that patients with more negative beliefs about the consequences of their illness had greater levels of depression and anxiety. The belief that the illness had serious consequences was also moderately, positively correlated with the belief that heart failure was a chronic or long-term condition. This might be expected in that the presence of symptoms which have persisted for a long time might reasonably represent a serious condition. From this, the duration of the illness might, therefore, be related to a belief in a chronic timeline and serious consequences. However, this was not found in this study with no correlations found between time with the illness and either timeline or a belief that the illness had serious consequences. The lack of any relationships may be because few respondents had heart failure of short duration. A picture emerges, then, of a belief system in which heart failure is perceived as a long-term condition with serious consequences and many symptoms, representing a significant emotional burden.

A number of correlations were found between treatment beliefs as shown in Table 6.16 and Figure 6.5. A moderate, positive correlation was found between concerns about



medication and the belief that medication use impacted on lifestyle. Such a relationship is perhaps unsurprising given that the impact of medication use on lifestyle can be considered a practical application of medication concerns. That these beliefs are related was supported by Factor analysis of the MUHFQ where the item, *'My tablets disrupt my life'* cross-loaded onto the concerns sub-scale and the impact of medication use on lifestyle sub-scale. It seems that, for some, the use of medication has a detrimental effect on everyday activities, leading to concerns about the use of medication.

Perceived medication knowledge correlated with all other treatment beliefs. Perhaps most interestingly, medication knowledge was weakly, negatively correlated with perceived social influences on medication use. This means that social influences, either through the advice of others or perhaps more importantly their practical help in terms of administering medication, had the effect of reducing an individual's knowledge about medication. This was illustrated in the interview data where wives, in particular, took control of medication management with resultant abdication of responsibility for medication management by their male partners. For example:

*'My wife could tell you all about the tablets I'm on, because, I don't take much notice of that. My wife does it' [P5]*

A significant difference was found between gender and social influences on medication use with men reporting greater influence. Although men were less confident in knowledge about medication than women, this difference was not statistically significant suggesting other factors may also be influencing medication knowledge such as complexity of the regime or cognitive abilities, for example.

A high degree of perceived medication knowledge was also related to a belief in the necessity of medication, fewer concerns and reduced impact of medication use on lifestyle suggesting that confidence in one's ability to understand the use of medication creates a more positive view of medication, although it is acknowledged that these relationships are weak.

A number of statistically significant correlations were found between illness representations and treatment beliefs (Table 6.16 and Figure 6.6). Specifically, a moderate, positive correlation was found between concerns about medication and a negative emotional response to the illness so that fears and anxieties were experienced in relation to both the illness and medication. Weak, positive correlations were found between the necessity of medication and illness representations. A high number of symptoms and a belief in a chronic timeline correlated with a belief in the necessity of

medication, suggesting that the construction of a model of a long-term illness with debilitating symptoms fuels the belief that medication is necessary. Medication knowledge was associated with increased illness coherence which represents a consistent finding of confidence or high self-efficacy in understanding both the use of medication and the illness itself.

In summary, illness representations in heart failure cluster around a model of a long-term condition with serious consequences and many symptoms, which represents a significant emotional burden for some. The belief that medication use impacts on lifestyle is related to more general concerns about medication, as expected. Perceived medication knowledge relates to a number of other treatment beliefs, with confidence in one's ability to understand the actions of medication and how it should be taken, promoting a more positive view of medication in terms of a stronger belief that medication is necessary and fewer concerns. However, when patients relinquish control of medication management to others, this knowledge may be threatened.

Negative emotions such as fear, anxiety and depression in relation to the illness go hand in hand with concerns about side-effects of medication and drug interactions, a relationship which would be expected. The view that heart failure is a long-term condition with many symptoms leads to the belief that medication is necessary for illness control. Self-efficacy is apparent in one's confidence in making sense of the illness (coherence) and in one's ability to understand the use of medication (knowledge).

### **7.2.2 Relationships between socio-demographic factors, illness representations, treatment beliefs and self-care**

Socio-demographic factors have been found to enhance self-care in a number of studies. Therefore, although not a main aim of the study, the relative influence of socio-demographic factors and beliefs might usefully be considered here. High levels of social support, higher economic status, increased length of time since diagnosis and little co-morbidity have all been reported to enhance self-care (Wu et al, 2007; Gary, 2006; Van der Wal et al, 2006; Carlson et al, 2001; Rockwell and Riegel, 2001; Evangelista and Dracup, 2000). The relationship between age and self-care is less clear with the suggestion that advancing age limits ability to self-care (Cline et al, 1999). However, Chriss et al (2004) and Evangelista et al (2003) found that increasing age was an independent, significant predictor of self-care with elderly patients demonstrating greater adherence to medication, diet and exercise advice than younger patients. Similarly, conflicting findings have been reported by Chung et al (2006b) and Gary (2006) in relation to adherence to a low sodium diet. In terms of gender, Heo et al (2008) found higher

perceived control and greater knowledge were associated with better self-care in men, whilst in women higher self-confidence and poorer functional status correlated with better self-care, perhaps indicating greater motivation. The presence of specific heart failure symptoms of fatigue, sleep difficulties, daytime sleepiness and forgetfulness reduce the ability to self-care according to Dickson et al (2007b) and Riegel et al (2007b). Functional ability as measured by the NYHA classification has been found to increase self-care in US studies by Dickson et al (2008) or decrease it (Wu et al, 2007; Rockwell and Riegel, 2001) either through a motivating effect or as a result of a reduced ability to self-care.

In this study, no significant relationships were found between socio-demographic factors and self-care. However, it is acknowledged that a number of factors may not have been adequately assessed using the SDQ, as this was designed to describe the socio-demographic characteristics of the sample rather than to determine relationships with self-care. There may also have been too little variation in the sample with regard to some characteristics to produce significant results. Given the disease trajectory, most participants were from older age groups so that few younger patients were represented. Purposive sampling of younger age groups would be needed to adequately determine the relationship between age and self-care. Similarly, as only 25.9% of the sample was women, this study may not have been adequately powered to determine the influence of gender on self-care. All participants described themselves as of white, British ethnic origin so the influence of ethnicity could not be determined. Levels of social support, rather than simply the presence of close personal relationships as determined by the SDQ, would need to be measured in order to determine the influence of social support on self-care, although the influence of others on medication use was considered. As the question assessing income was removed from the final version of the SDQ, economic status was determined only by occupation which, considering that most of the sample were retired, may not adequately assess this factor. Similarly, since more than half of the sample reported having no formal qualifications, there may have been too little variation in terms of education to adequately determine the relationship with self-care. Similarly, little variation in levels of reported co-morbidity may have meant that the influence of this factor could not be accurately determined. Functional ability as assessed by the NYHA was not related to self-care in this study. A more objective measure of illness severity, such as an echocardiogram, may be needed in order to determine the influence of this factor. Therefore, although it is suggested by this study that socio-demographic factors have limited influence on self-care, further research into individual factors is recommended.

From the CSM and studies by Morgan (2008), Cherrington et al (2006) and Voelmeck (2006), it would be expected that the belief in a chronic illness with serious consequences,

strong personal and treatment control beliefs and high illness coherence would motivate individuals to self-care. A strong, negative emotional response to the illness could either be a motivating factor or be disabling, here the literature is equivocal. The presence of depression has been related to poor self-care in studies by Holzapfel et al (2009), Riegel et al, (2007b), Dickson et al (2006) and Lesman-Leegte et al (2006). Non-adherence to medication is reportedly three times higher in depressed patients compared to those who are not depressed (DiMatteo et al, 2000). However, negative emotions, such as fear or worry, may also be motivating factors to self-care. In relation to beliefs about causation, it is hypothesised that the belief that the illness was caused by lifestyle factors would result in lifestyle changes. The symptom of daytime sleepiness has also been linked to poor self-care (Riegel et al 2009c).

In this study, a number of weak but statistically significant correlations were found between illness representations and self-care. These are presented in Table 6.16 and Figure 6.7. A meta-analysis of studies using the IPQ-R found weak to moderate correlations between beliefs and behavioural outcomes (Hagger and Orbell, 2003). Therefore, the strength of relationships found in this study can be considered comparable to similar studies in other illness populations using this theoretical framework.

Illness coherence was most strongly related to self-care, the belief that the illness makes sense perhaps enabling an understanding of the rationale for individual self-care behaviours. This describes the confidence in one's ability to understand the illness and the required management, or self-efficacy beliefs (Bandura, 1977). Other hypothesised relationships were also supported with the belief that heart failure is a chronic illness, has serious consequences and can be controlled by treatment all positively, though weakly, correlated with self-care. No statistically significant correlations were found between personal control and emotional response to the illness, and self-care. A limited negative emotional response reported by participants in this sample may explain this lack of correlation. In addition, that negative emotions may be enhancing or limiting factors in different individuals may mean any overall correlation with self-care is cancelled out.

No significant correlations between beliefs about specific causes of heart failure and self-care were found. An analysis of causative factors revealed general disagreement that the listed items caused the illness and few additional causes were suggested in the open question. It seems that the cause of the illness is frequently unknown and individuals do not seek to attribute the illness to a specific cause so that beliefs about causation may be relatively unimportant in terms of behavioural outcomes in heart failure. Only the symptom of sexual difficulties was weakly, negatively correlated with self-care. Although sexual

dysfunction is a recognized effect of heart failure, no studies have related this to self-care. However, the impact of sexual difficulties on emotional status and social relationships, for example, seems likely to have a negative effect on well-being and self-care. Given this weak relationship, further studies would be needed to explore this further.

In relation to treatment beliefs, according to the extended CSM, a strong belief in the necessity of medication enhances adherence while concerns about medication reduce adherence. According to Horne (1997) the balance between necessity and concerns (the necessity-concerns differential) may be more predictive than either set of beliefs alone. From the literature, medication knowledge (Wu et al, 2008; Ekman et al, 2006; Toren et al, 2006; Cline et al, 1999) is predicted to enhance self-care. However, as perceived rather than actual medication knowledge was assessed in this study, findings may not be directly comparable to published studies. High levels of social support have been found to enhance medication adherence (Chung et al, 2006a), so that it could reasonably be assumed that social influences on medication use might also enhance self-care. However, the beliefs of others, particularly if these are misconceived may contribute to reduced adherence (Furze et al, 2002). Although, aspects of the impact of medication use on lifestyle, such as the effects of diuretics, have been described in the literature, their effects on medication adherence have not been addressed. It is hypothesised that the belief that medication use impacts on lifestyle might result in reduced medication adherence and self-care.

In this study, a number of moderate and weak, but statistically significant correlations were found between treatment beliefs and self-care (Table 6.16 and Figure 6.7). Moderate, positive correlations were found between medication knowledge and beliefs about the necessity of medication and self-care, as predicted. This means that the belief that medication is necessary for controlling the illness or its symptoms and confidence in one's ability to understand the use of medication and take it appropriately, enhances self-care. Presumably this relates to the specific self-care behaviour of medication adherence, although this cannot be confirmed using the LAYHFQ as only a total self-care score was used.

A weak, negative correlation was found between the impact of medication use on lifestyle and self-care. Therefore, the belief that medication use impacts on lifestyle correlates with reduced self-care, as predicted. Similarly, concerns about medication also correlated with reduced self-care, although this relationship was not significantly significant. This suggests that the impact of heart failure medication such as the effects of diuretics, difficulty in going out, managing the medication regime and monitoring the effects of

medication are more important in predicting medication adherence than more general concerns about medication such as drug dependency or worries about side-effects, as described in the BMQ.

A weak, negative correlation was found between social influences on medication use and self-care. That a high degree of social influence on medication use has been found to have a detrimental effect on self-care seems counter-intuitive. However, it was suggested by the qualitative data that, where spouses took control of medication management, participants had reduced knowledge of medication. This was also found in the survey where a weak, negative correlation was found between medication knowledge and social influences on medication use. This is in contrast to the findings of Chung et al (2006a) who found that patients with a spouse were more knowledgeable about the names and doses of medication. Given that medication knowledge was the most highly correlating factor with self-care, this finding seems to describe a situation where participants are less confident about their knowledge about medication due to the influence of spouses on medication management, resulting in a reduced ability to take medication appropriately. It is further suggested that this lack of confidence in understanding the use of medication is also apparent in terms of the illness as a whole, as illness coherence was the most strongly correlating factor with self-care. This means that individuals who lack confidence in understanding their illness and its treatment are less able to make decisions about self-care.

Due to the high number of correlations found in this study, those factors that explained most of the variance in self-care behaviour were explored using multiple regression. From this analysis, illness representations alone accounted for 23% of the variance in self-care. When treatment beliefs were added, 46% of the variance was accounted for. Three factors were significant predictors of self-care - medication knowledge, a belief in the illness having serious consequences and the impact of medication use on lifestyle (Figure 6.8). As two of these factors are beliefs about treatment, it is likely that these relate to the specific self-care behaviour of medication adherence.

Perceived medication knowledge was the strongest predictor of self-care in this analysis. Within the context of the interview data, the statement below illustrates a high degree of confidence in medication knowledge which has been shown here, to be predictive of effective self-care:

*'I know what each of them is supposed to do really. Atorvastatin, that's for my cholesterol, the aspirin's to keep the blood thin, atenolol, the beta-blocker, that slows*

*my heart down a little bit and then I'm on a couple of other things – I think there's a water tablet in there as well just to help with fluid retention' [P7]*

As no studies have addressed confidence in medication knowledge, further research is needed to determine the relative influence of accurate knowledge compared to perceived knowledge or confidence in one's ability to understand the use of heart failure medication, on self-care.

The impact of medication use on lifestyle was also found to be a significant predictor of self-care. However, it should be remembered that the internal consistency of this sub-scale was moderate. Further development and testing of the questionnaire is, therefore, advocated. This factor is related to general concerns or worries about medication and so is consistent with the necessity-concerns framework of treatment beliefs according to Horne et al (1997). Rather than generalized concerns, this factor addresses the specific, practical impact of the use of medication on lifestyle, such as the difficulty in adhering to the treatment regime when away from home or the effects of medication, for example the need for frequent urination due to diuretics, and the work involved in monitoring the effects of the medication as illustrated by:

*'I am on water tablets but once you're getting rid of it, you go to the toilet every half hour or something like that which is difficult when you are out' [P3]*

*'We used to visit my son in Herefordshire, but I don't drive there now. It's not so much the driving it's that I always seem to have an appointment with the nurse or doctor to check the effects of the tablets' [P1]*

The disruptive effect of heart failure medication, particularly diuretics, is well documented (Cowie et al, 1999). However, the impact this has on self-care has now also been demonstrated. Similarly, the concept of work in relation to managing a long-term illness as described by Glaser and Strauss (1967) can be applied to heart failure in that considerable effort is required, particularly in terms of medication management, with resulting negative effects on adherence and self-care.

The only illness representation predictive of self-care was the belief in the illness having serious consequences:

*'To me, it's very serious. The way I feel, it's bad' [P10]*

A serious model of the illness seems to act as a motivating factor to self-care so that actions to negate or minimise these consequences are more likely to be carried out.

In summary, a number of correlations between illness representations, treatment beliefs and self-care were found suggesting a complex interaction between beliefs and behaviour. Self-care was enhanced by the belief that the illness is a long-term condition with serious consequences which can be controlled by medication, as predicted by the CSM and published literature. The belief that the illness 'makes sense' also enhances self-care, as predicted. Perceived medication knowledge, a belief in the necessity of medication, few concerns and, importantly, the belief that medication has limited impact on lifestyle was also related to enhanced self-care. Interestingly, social influences on medication use reduced self-care which is in contrast to many published findings. As medication knowledge was found to be the most significant predictor of self-care, it seems that the influence of others reduces this confidence which might explain the detrimental influence of family members on the ability of patients to make self-care decisions. The importance of confidence or self-efficacy beliefs is also supported by the fact that illness coherence was the illness representation most strongly correlated with self-care. There was lack of support for some hypothesised relationships, most notably between socio-demographic factors and self-care, although it may be that there was insufficient variation in a number of these factors to establish relationships.

From the regression analysis, illness representations and treatment beliefs together accounted for 46% of the variance in self-care. Three factors were significantly predictive of self-care, namely, perceived medication knowledge, the impact of medication use on lifestyle and the belief that the illness had serious consequences. Strategies aimed at enhancing these beliefs and minimising the impact of medication use on lifestyle, may, therefore, lead to enhanced self-care, discussed in section 7.6.

### **7.3 CRITIQUE OF THE METHODOLOGY AND METHODS**

This section evaluates the research design, methodology and methods and considers the extent to which these were effective in achieving the aims of the research. The purpose of using a mixed methods design was not only to develop the questionnaires but also to 'add value'. That is, to gain a better understanding of the research problem than if either qualitative or quantitative methods had been used alone (Creswell and Plano Clark, 2007). The interviews provided rich description of the experience of living with heart failure from a patient perspective so that the questionnaires could be modified to be meaningful and relevant to this population.

The main strength of the survey, using quantitative methods, was the ability to determine the relationships between beliefs and behaviour in a larger, representative sample so that



the results could be generalised to a wider population of heart failure patients (Kruger, 2003). In the discussion of these relationships, the qualitative findings have also been used to illuminate or help explain the results and provide the context within which beliefs and self-care occur. Although methodological triangulation was not the main purpose of using mixed methods here, overall agreement between the qualitative and quantitative findings, enhanced the reliability of the findings. A small number of contradictions were found, particularly in relation to the emotional response to the illness and related concerns about medication, which was more prevalent in the interview sample.

However, some dilemmas and tensions were apparent in using a mixed methods design. Firstly, given the large volume of data generated by the interviews, the selection of the most relevant and important themes to be included in the questionnaires required making some difficult decisions. Creswell and Plano Clark (2007) recognise that selecting themes for further investigation is difficult in a mixed method, instrument development model. Rigorous analysis was therefore required in order to justify the inclusion (or exclusion) of themes. For example, from the interview data, the themes of medication knowledge, social influences on medication use and the impact of medication use on lifestyle were carried through to phase two as they seemed to be frequently described by participants and potentially relevant to medication adherence and self-care. The self-care domain of managing symptoms and the emotional and social effects of the illness was also constructed since this was frequently described by the interview participants and is consistent with the DH (2006a) definition of self-care. Furthermore, this theme could be visualised according to the CSM in which coping responses are aimed at both the illness and emotional response to the illness.

A further dilemma was apparent in drawing conclusions from results which were inconsistent between the two phases of the study. For example, a strong, negative emotional response to the illness was a prevalent feature of the interview data but this was less apparent in the survey. The philosophical paradigm in which the research is located is relevant here, in that when a pragmatic stance is taken (Morgan, 2007) the findings of one method are not necessarily given priority over the other. This means there is freedom to explain the data in different ways. In this example, the negative emotional response found in the interview data could be explained as either a result of selection-bias in this sample or a limited ability to draw out deep emotions using quantitative methods such as the IPQ-R (HF). In relation to illness coherence, the survey results suggested a strong belief that the illness made sense. However, when viewed in the context of the interview findings, coherence was not demonstrated in relation to other illness

representations or behaviour, leading to the conclusion that illness coherence could be interpreted in different ways. This is discussed further in section 7.5.

### **7.3.1 Phase one - the qualitative interviews**

A number of points are raised in relation to the methodology and methods of phase one, the qualitative interviews. Firstly, in terms of sampling and recruitment, the purpose was to select a diverse range of participants in order to yield rich, descriptive text (Denzin and Lincoln, 2003). With this aim, a purposive sample in terms of age and gender was achieved as planned. The original intention was to approach patients from across three PCTs in order to recruit from a broad geographical area with a potentially more diverse population. In the event, recruitment was from one site only (Site A) as determined by data saturation which may have limited the diversity of the sample. However, as there were few significant socio-demographic differences between Sites A and C in the survey sample, it is unlikely that there was much diversity in terms of patient characteristics across the three sites.

Personal introduction by the patients' HFN was successful in terms of recruiting sufficient sample sizes for both the interviews and the survey and was preferable to a postal invitation in terms of response rate (De Vaus, 1996). The sample size for the interviews was considered to be sufficient given that the final number of interviews was determined by data saturation (Polit and Hungler, 2001). Although the HFNs were given careful, explicit instructions about the inclusion and exclusion criteria there was no guarantee that they did not further pre-select patients. For example, those most compliant with treatment may have been selected in order to reflect favourably on the practice of the HFNs. Such pre-selection could have been avoided by selecting individual patients from the heart failure database before introduction. However, this process would have increased the period of data collection considerably as participants would have only been available for recruitment at their next home visit or clinic appointment, which may have been some weeks away.

In addition to any pre-selection, interview and survey participants also *chose* to take part (self-selection). The effect of this was perhaps most apparent in the interview sample where it is suggested that patients who were particularly fearful or anxious may have welcomed the opportunity to talk about their illness and so were more likely to consent to take part. The likely characteristics of non-responders in the survey have been considered in determining the extent to which the sample was representative of the heart failure population (section 7.3.2).

The lack of pilot interviews meant that the interview schedule and process of conducting the interviews were not tested. With hindsight this would have been beneficial especially considering that the process of data collection was altered slightly in the course of collecting the data in that spouses were asked to only give their views at the end of the interview. However, it is acknowledged that the presence of spouses in the room may still have influenced the participant's responses and introduced some bias (Oppenheim, 2002). On a positive note, this observed shared illness experience between the participant and spouse was an important finding and helped develop the theme of social influences on medication use.

From a methodological point of view, Shaw (2002) argues that revealing a true lay perspective of illness may not be achievable. Certainly, participants seemed to attempt to explain their heart failure in medical terms, often using the same terminology, although not necessarily demonstrating full understanding. It could also be argued, however, that in western society, the dominance of the biomedical model of health has meant that viewing illness in these terms has become the established cultural norm.

In conducting the interviews, the relationship between the researcher and participant was recognised as reciprocal. Denzin and Lincoln (2003) assert that it is neither realistic nor desirable to view qualitative data as totally objective and free from personal beliefs and biases. A major strength of the interviews was the development of a trusting relationship so that the beliefs of participants' could be explored. This may have been especially important in eliciting emotional responses to the illness. However, in order to be able to carry out meaningful cross-case analysis, attempts were made to standardise the interviews through the use of an interview schedule which also helped ensure that important questions were not missed.

Analysis was carried out according to the framework method (Miles and Huberman, 1994) using deductive and inductive reasoning, consistent with a mixed method approach. The use of NVivo 7 made the data easier to manage compared to previous experience of analysing textual data. Arguably, it also facilitated a more systematic approach to analysis as the text could be more easily retrieved and interrogated so that analysis may have been more thorough, although this is difficult to confirm. As in the process of collecting data, the researcher cannot be viewed as an objective outsider but integral to the process of data interpretation and analysis. Field notes, though secondary to the transcripts of the audio-tapes, were also useful in developing themes and reviewing the quality of the interviews as they were conducted.

In determining trustworthiness or '*the extent to which the findings of the qualitative data represent reality*' (Guba and Lincoln, 1995, p.186), credibility, transferability, dependability and confirmability were considered. In terms of credibility, an attempt was made to carry out member checks to make sure the interview findings were true to the experience of the participants. Although participants were invited to check the accuracy of the transcripts and contribute to the analysis by viewing the results, few participants contributed further. This might have been because they were completely happy with the accuracy and interpretation of the results. However, it is also likely that participants' chose not to engage with the research process beyond the initial interview which is a common experience according to Bryman and Burgess (1994). The transferability of the findings is limited by the lack of a representative sample, although qualitative research is not primarily concerned with representativeness and therefore, generalisability. Holloway and Wheeler (1996) suggest that as long as the characteristics of the sample are described accurately and a clear decision trail is given in relation to data analysis, readers can determine if the results can be applied to their own setting. Theoretical and methodological choices have been discussed throughout which is said to enhance the dependability of the findings. Confirmability has been established by linking quotes from individual participants through to the development of themes and conclusions. By following these criteria, it has been demonstrated that the findings of the qualitative phase may be considered trustworthy.

Ethical principles of autonomy, veracity, informed consent, confidentiality and anonymity were applied in all stages of recruitment, data collection, data storage and analysis (Guillemin and Gilham, 2004). Equal opportunity of access may have been compromised to some extent as those heart failure patients unable to speak or read English were excluded from the research. However, given that only 6% of heart failure patients registered to the three heart failure services were known to be of BME origin (PCT Trust data, 2009) with a similar figure in the County overall (KCC website, 2010), that the sample consisted only of patients who described themselves as 'white, British', could reasonably be expected to have occurred by chance.

### **7.3.2 The pilot study and phase two - the quantitative survey**

In the adaptation or development of the questionnaires, determining what themes to measure required a selection process based on the relative strength of the interview findings and their relevance to the aims of the study. General principles of questionnaire design (Oppenheim, 2002) were followed in the initial development of the questionnaires with consideration given to layout, the wording of questions and the response format, for

example. Reversed and filler questions were included in order to minimise acquiescence bias (Coolican, 2009).

The development of the LAYHFQ using a NGT with an expert group of HFNs was effective in determining self-care behaviours in heart failure from a nursing perspective. NGT, using a mixed methods approach, was carried out based on a process described by Potter et al (2004). The main advantages were that it was easily understood by the HFNs and it enabled their views to be determined in a short period of time which was important given the limited time available to collect the data. That the behaviours identified were generally consistent with self-care behaviours advocated by Riegel et al on behalf of the AHA (2009a) supports the adequacy of this method. Determining the relative importance of self-care behaviours using a NGT was more difficult as all items were highly scored. This was perhaps unsurprising since the remit given to the HFNs was to identify important self-care behaviours. The scoring system was, however, useful in excluding those behaviours least specific to heart failure or not applicable to all heart failure patients. Hence, a healthy diet was least highly scored and subsequently excluded from the final questionnaire as it was not specific to heart failure nor recommended advice to heart failure patients in the terminal stages of their illness.

The decision to use the interview data as well as NGT in the development of the LAYHFQ enabled a patient perspective of self-care to be included. Findings from the NGT indicated that the HFNs emphasised adherence to medication and reporting and help-seeking behaviours in their definition of self-care, which describes a medically-orientated viewpoint. Patients also described the importance of maintaining a positive attitude, managing negative emotions and making an effort to maintain social networks. This was ultimately developed into the domain of managing symptoms and the emotional and social effects of the illness, in the LAYHFQ. In this sense, the patient perspective of self-care was more in keeping with the DH (2006a) definition compared to the health professional perspective.

The aim of the pilot study was to test the processes of recruitment, data collection and analysis and enable further development of the questionnaires in preparation for the main survey. In terms of recruitment, the pilot study was effective in establishing that the questionnaires could be distributed in sufficient numbers over a reasonable timescale by the HFNs. The likely response rate in the main survey was also able to be estimated. A limitation of the pilot study was that the process of collecting data by telephone or in a face-to-face interview could not be tested as no respondents in the pilot sample chose to complete the questionnaires in this way. However, face-to-face completion of the

questionnaires was carried out with the clinic patients during member checks which enabled some piloting of the procedures to occur. As no difficulties were encountered in the collection of the main survey data, the lack of pilot interviews appeared to have had limited impact. With hindsight, the pilot study could have been designed to test all methods of data collection by only offering one method to different groups of participants. However, by doing so, the preferred method of data collection would not have been known.

Analysis of the pilot questionnaires meant that those questions which had not been answered by a number of respondents (missing data) could be re-designed or omitted in the final versions of the questionnaires. The process of going through the questionnaires, face-to-face, with a small number of heart failure patients attending a clinic was especially useful in identifying ambiguous questions or questions which were difficult to answer. On reflection, a second pilot study might have been carried out following these amendments so that the final questionnaires could have been more rigorously tested prior to use. However, this would have reduced the size of the available sample for the main survey and it is likely that a second pilot would have led to yet further amendments.

The process of setting up a pilot data file in SPSS and carrying out anticipated statistical analysis was important due to limited prior experience in statistical analysis. The database was then easily amended for use with the main data set.

In the main quantitative survey, the sampling strategy was important in terms of determining the representativeness of the sample and hence the generalisability of findings. In order to achieve an adequate response rate, recruitment was changed from a postal method to a personal, face-to-face introduction by the HFNs. This meant that the size of the available population was greatly reduced as it was now limited to those in face-to-face contact with the HFNs either through home or clinic visits. A probability sampling strategy was, therefore, rejected given that the whole population now effectively needed to be approached, described by Polit and Hungler (2001) as total or whole population sampling.

In order to determine the extent to which the findings can be considered representative of the heart failure population, the characteristics of the sample need to be compared to those in the wider heart failure population. Data in relation to age, gender, social situation and ethnic origin of the heart failure population across the three sites were available from the HFN services. Other socio-demographic and illness-related characteristics of qualifications, the presence of co-morbidities and NYHA classification were not stored

centrally on the Trust databases but only in individual notes and so could not be easily retrieved and compared.

Although sample sizes from the three sites were unequal, no significant differences were found in terms of age, time with the illness, gender, social situation, qualifications, the presence of co-morbidities or NYHA classification between Sites A and C. There were too few cases at Site B to carry out similar analysis. Overall, where examined, the samples can be considered to come from a single population.

The average age of the heart failure population in the locality is 72.9 years (PCT Trust data, 2010). The age of the heart failure population nationally is estimated to be 73 years (NICE, 2010). In this sample, the average age was 70.9 years which is slightly younger but generally comparable to both the local and national picture. One explanation might be that older patients may have been in poorer health and so were not invited to take part in the study according to the exclusion criteria. In terms of gender, 31.2% of heart failure patients in the locality are female and 68.8% are men. In this sample, 25.9% were women and 74.1% were men so that fewer women were included than might be expected. As women with heart failure tend to be older (NICE, 2010) they may have been more likely to be excluded based on poor health. Only 6% of patients with heart failure in the locality are of BME ethnic origin (KCC website, 2010). In this sample, no BME ethnic groups were represented which may have occurred by chance or may be partly explained by the requirement that participants were able to read and speak a sufficient level of English to take part in the study. According to local data, 76.4% of heart failure patients live with their spouse or other family member whilst 23.6% live alone. In this sample, 19.3% lived alone and 79.5% lived with a spouse or family member. Again, the sample may reasonably be considered representative of the heart failure population in terms of living situation. That some participants may have needed help in completing the questionnaires might explain the slightly lower number of participants living alone than perhaps might be expected.

Finally, it is recognised that the sample was drawn from a population of heart failure patients who were managed by a specialist HFN and GP. Alternative models of service delivery exist in this locality and nationally. For example, patients may be managed by a GP only, or Community Matron and GP, for example. It might be reasonable to assume that patients in this study had greater specialist education which may have resulted in fewer misconceptions and had enhanced self-care support compared to those cared for according to other service models. However, the involvement of specialist HFNs in care is becoming the norm within the NHS (BHF, 2009) so patients in this sample may be typical of the heart failure population nationally. In conclusion, the sample can be considered

representative of the heart failure population locally and, where it is possible to be determined, nationally. Hence, the findings of this study can reasonably be generalised to the wider heart failure population, especially those cared for within a shared care model of service delivery with specialist nursing input.

In relation to recruitment, fewer questionnaires were delivered than anticipated due to a number of unforeseen circumstances. At Site B, staffing pressures meant that far fewer envelopes were delivered than anticipated. At Site C, recruitment was limited by the size of the available population. However, given the overall response rate of 50.4%, the target sample size of 156 respondents was achieved.

As in the qualitative phase, although the HFNs were given careful, explicit instructions on the inclusion and exclusion criteria there is no guarantee that they did not further pre-select participants. However, given that the number of envelopes handed out effectively included the total available population, especially at Site C, pre-selection is likely to have been minimal.

It is possible that the questionnaires were completed by family members or friends rather than the heart failure patients themselves. The degree to which this might have occurred is difficult to judge but some involvement of others seems likely given that many of the participants were elderly, in poor health and had co-morbidities. The consequences of this in terms of the validity of the results may depend on the nature of the involvement. For example, where spouses or other family members acted simply as scribes, the influence on the results was probably minimal. Alternatively, completion of the questionnaires may have been collaborative with participants and their spouses discussing the responses. This seems most likely, given that the illness was often viewed as a shared experience by patients and spouses in the interview sample. Family members may, alternatively, have completed the questionnaires on behalf of the patient without their direct involvement. It is difficult to suggest how this could have been avoided as even in the face-to-face interviews, which allowed some degree of control by the researcher, the involvement of family members in data collection was apparent.

In terms of data analysis, descriptive and inferential statistics were successfully used to describe the data and determine relationships between variables, the exception was some Chi-squared ( $X^2$ ) analysis where too few cases were available for meaningful analysis. Since the aim of this analysis was to determine differences in socio-economic characteristics between the three sites, this was not integral in meeting the aims of the research.



#### 7.4 OVERALL VALIDITY AND RELIABILITY OF THE QUESTIONNAIRES

The consideration of the validity and reliability of the questionnaires is important in determining their overall value and the strength of the findings. The IPQ-R (HF) demonstrated good internal consistency both in the questionnaire as a whole and the separate domains, demonstrated by Cronbach's  $\alpha \geq 0.7$ . In terms of validity, overall, there was agreement between the qualitative findings and those of the IPQ-R (HF), for most domains, demonstrating concurrent validity. The IPQ-R has also been extensively tested for validity and reliability in a variety of illness groups (Moss-Morris et al, 2002) and minimal changes were made to this questionnaire in its adaptation to the IPQ-R (HF). The strengths of the IPQ-R, therefore, lend support to the conclusion that the IPQ-R (HF) is both valid and reliable in a heart failure population.

The MUHFQ, incorporating the BMQ, demonstrated good consistency in four out of the five domains ( $\alpha > 0.7$ ). However, the impact of medication use of lifestyle domain was only moderately reliable in this sample ( $\alpha = 0.56$ ). Further development and testing of the reliability of this sub-scale is, therefore, recommended before further use in research or used in clinical practice. In terms of validity, concurrent validity was demonstrated by general agreement between the findings of the qualitative data and the findings of the MUHFQ. Factorial validity, as determined by principal components analysis, was supported in that a 5-factor structure was described according to the theoretical domains of treatment beliefs. However, the cross-loading of one item on both the impact of medication use on lifestyle domain and the concerns domain, again, suggests a need for further development and testing of these constructs.

The LAYHFQ demonstrated good internal consistency overall ( $\alpha = 0.77$ ), but this could not be demonstrated in relation to the individual domains ( $\alpha \leq 0.7$ ). This meant that only relationships with total self-care could be reliably determined. Similarly, factorial validity was not established, with principal components analysis failing to support the existence of the theoretically derived self-care domains. It is, however, worth noting that the EHFSBS also fails to demonstrate factorial validity and uses a total self-care score (Jaarsma et al, 2003). Given these findings, the usefulness of dividing self-care into separate domains is discussed in section 7.5. The LAYHFQ questionnaire was developed and reviewed by specialist HFNs and so can be said to have content validity. Findings were consistent between the qualitative and survey data, demonstrating concurrent validity.

In conclusion, the questionnaires, overall, can be considered valid and reliable for use in this study. However, it is recognised that other measures of reliability and validity such as stability, predictive, convergent and discriminant validity might also be tested.

## **7.5 THE USE OF THE THEORETICAL FRAMEWORK**

An extended CSM, incorporating treatment beliefs was used to guide data collection and analysis. From this analysis, a number of points can be made about the use of the model in this study.

As discussed in Chapter four, categorising emotions in the analysis of the qualitative data was problematic in that negative emotions could be categorised as an emotional response, psychological consequence or coping response, as argued by Ogden (2003). However, in-depth interviews, to some extent, overcame this as the context in which the emotion was described was known. Similarly, categorising some items as symptoms or consequences was, at times, difficult. For example, sexual difficulties could be considered a symptom of heart failure or a consequence of it. In general, where items were recognised symptoms of heart failure according to the literature, they have been categorised as such. Whilst this was relevant in the analysis of the qualitative data in order to develop the symptom scale in the IPQ-R (HF), it was less relevant in analysing the survey data where the belief that the illness had serious consequences was assessed rather than the nature of those consequences.

Coherence was also a difficult concept to analyse as it may be being defined differently depending on the methodology used. This conclusion has been drawn from the analysis of the qualitative and quantitative data and a review of other published literature. Coherence can be defined as a meta-cognition or belief about the extent to which the illness makes sense (Moss-Morris et al, 2002), as measured by the IPQ-R and the IPQ-R (HF) (Cherrington et al, 2006 and Voelmeck, 2006). In this way illness coherence is related to self-efficacy beliefs (Bandura, 1977). Illness coherence may also be demonstrated through the accuracy of illness representations and the congruence between these beliefs and behaviour when measured by qualitative methods (Horowitz et al, 2004). Hence, a strong belief that the illness makes sense is described in studies using quantitative methods but limited demonstrated coherence is described in qualitative studies.

In relation to treatment beliefs, the necessity-concerns framework proved a useful way of describing beliefs about medication. However, this framework was further developed in the MUHFQ to include three additional domains. From the interview data, concerns about medication were described in practical terms as the impact of medication use on lifestyle. Perceived knowledge about medication was described with the actions, names and the number of tablets specified. Social influences on medication use were also apparent.

Factor analysis supported these constructs and multiple regression analysis confirmed that these beliefs were predictors of self-care behaviour. Hence, in heart failure, beliefs about medication could be extended beyond the framework proposed by Horne et al (1999) to usefully include additional sets of beliefs.

The CSM describes behavioural outcomes as being influenced by illness representations and treatment beliefs. Relationships between these beliefs and self-care were demonstrated in this study, supporting the use of the CSM in explaining behaviour. However, the theoretically proposed constructs of adherence to recommended lifestyle advice, adherence to medication, monitoring symptoms, managing symptoms and reporting and seeking help (Dickson et al, 2006) were not supported by factor analysis in either the LAYHFQ or the EHFSBS (Jaarsma et al, 2003). The additional construct of managing the emotional and social consequences of the illness, according to the CSM, was also not supported by factor analysis in the LAYHFQ. Rather, self-care seemed to consist of a number of unrelated behaviours as also demonstrated by the lack of internal consistency. The implications of which are discussed below.

## **7.6 IMPLICATIONS FOR PRACTICE AND RECOMMENDATIONS FOR FUTURE RESEARCH**

A number of implications for clinical practice, especially nursing, are suggested. Three beliefs were identified which were significantly predictive of self-care - the belief that the illness had serious consequences, perceived knowledge about medication and the belief that medication use impacts on lifestyle. It seems likely that treatment beliefs influence medication adherence, rather than other self-care behaviours although this cannot be confirmed using the LAYHFQ.

Targeted interventions aimed at addressing these beliefs may, therefore, enhance self-care. An example of such an intervention is described by Petrie et al (2002). In this study a brief, in-hospital intervention aimed at changing beliefs was effective in improving functional ability in patients following MI. The intervention consisted of three, 30-40 minute individual patient sessions conducted by a psychologist. The first session consisted of a brief explanation of the pathophysiology of the disease and an explanation of common symptoms and terminology. Cardiac and non-cardiac symptoms were discussed. Using individual patient scores on the IPQ-R, beliefs about the illness were explored and any misconceptions were addressed, particularly the belief that stress was a single causal factor in the development of the disease. In this way the patients' causal model of the illness was broadened to include lifestyle factors. The second session built on these beliefs, focusing on developing a plan for minimising future risk by altering risk factors

relevant to the individual and increasing beliefs about control of the illness. Highly negative beliefs about the consequences of the illness were challenged and a personal development plan was devised. In the third session, the action plan was reviewed and concerns the patient had about their medication were explored. The need to take medications consistently and the difficulty of relying on symptoms as a guide to medication use were discussed.

Many of the features of this type of consultation will be familiar to nurses working with heart failure patients and it would seem feasible that a similar approach might be used to explore illness and treatment beliefs in heart failure, addressing any misconceptions. In particular, the belief that the illness does not have serious consequences might be addressed as this was found to impact on self-care. However, high levels of anxiety and despair may be present so there is a need to balance a realistic picture of a chronic illness with serious consequences against heightened negative emotions. Other specific misconceptions such as the belief that the illness is acute and short-lasting or is cyclical in nature might be addressed as both were found to be correlated with reduced self-care. Similarly, the belief that the illness cannot be controlled by medication may result in medication non-adherence. Other beliefs may exist which are unique to the individual. A broad discussion of the patient's beliefs about the illness and its treatment should elicit these views, presenting an opportunity for misconceptions to be challenged.

Knowledge about medication has been shown to be important in terms of the ability to take medication appropriately (Ekman et al, 2006; Toren et al, 2006; Cline et al, 1999). However, perceived knowledge or the confidence in one's ability to understand the use of medication and take it appropriately should also be explored. Threats to knowledge, such as changing the brand of medication, frequent changes to the medication regime, particularly after admission to hospital and the practice of up-titration of many heart failure medications should be recognised and avoided where possible. Where changes are necessary, efforts should be made to ensure knowledge and confidence are maintained at each change in medication or dose. The influence of family members, especially spouses on medication management should also be considered as it is suggested that where others take control of medication management, the individuals confidence in their ability to understand the actions of medication and take it appropriately, may be reduced. Given some patients reliance on family members for practical medication management, the loss of this support through bereavement, for example, may make this group of patients particularly vulnerable to poor self-care, making education a priority in these individuals.

The impact of medication use on lifestyle should be recognised and explored and ways in which this might be reduced, for example, by altering the timing of medication, should be discussed and agreed with the patient.

The intervention described by Petrie et al (2002) is specific to illness and treatment beliefs according to the CSM, however, other interventions exist which may differ in their theoretical perspective. In a systematic review of interventions designed to change maladaptive beliefs in CHD, Goulding et al (2010), suggest that cognitive behavioural and counselling/educational interventions can be effective in changing beliefs. What is important is that nurses and other health and social care professionals have sufficient knowledge, skills and experience in that intervention to effectively explore and address beliefs and behaviour, related to heart failure. Further education may be needed to bridge any gaps in their knowledge and skill base.

From a health and social care policy perspective, as found using a NGT, HFNs focused on adherence to medication and reporting and help-seeking behaviour in their vision of self-care in heart failure. However, government policy (DH, 2006a) encompasses a much broader and more inclusive definition of self-care in long-term conditions, including maintaining social and psychological well-being. These aspects of self-care were also seen as important by patients in this study. It seems that to truly embed the principle of self-care, health professionals need to look beyond adherence behaviour, to a more holistic view of the patient and the social context in which the illness occurs.

In terms of further research, although the primary purpose of collecting socio-demographic data using the SDQ was to describe the sample rather than to determine relationships with self-care, a number of studies, for example, Riegel et al (2007b) suggest relationships between socio-demographic variables and self-care. As these variables were not fully addressed in this study, further research is needed to determine their relative influence on self-care in a UK, heart failure population. No distinction was made in the main survey between treatment beliefs and adherence to different medications. The interview data suggested that patients may hold different beliefs about different medications, for example, doubts about the necessity of statins once cholesterol levels have been reduced; concerns about the side-effects of aspirin and the impact of diuretics on lifestyle. It might, therefore, be expected that adherence to different medications also varies as suggested by Albert (2008). An exploration of beliefs in relation to specific heart failure medications would inform the development of interventions addressing potentially different beliefs.

Although the questionnaires have been shown to be reliable and valid in this population, further psychometric testing of the questionnaires might be carried out, for example to test for concurrent validity and external reliability. Internal consistency of the impact of medication use on lifestyle sub-scale in the MUHFQ demonstrated only moderate reliability so further exploration of this concept and its relationship to self-care is advocated, perhaps through exploratory qualitative methods.

It has been argued here, that individual self-care behaviours are separate and not necessarily related to each other according to the theoretical domains of self-care as advocated by many authors, including Dickson et al (2006). Therefore, in this study, only total self-care can be considered a reliable measure. The LAYHFQ could be used clinically as a measure of total self-care as it has been shown to have content validity and internal reliability in this population. However, it is recommended that this questionnaire be further developed so that each individual behaviour is assessed using three or four items as De Vaus (1996) argues that assessing behaviour using multiple items enhances reliability.

In terms of the use of the CSM, further research is advocated on the influence of illness coherence, either as the self-efficacy belief that the illness makes sense or as demonstrated through fewer misconceptions and the congruence between beliefs and behaviour. Similarly, the influence of actual medication knowledge and the confidence in one's ability to understand the use of medication, on self-care might be further explored in order to determine whether education alone or in combination with, for example, motivational interviewing is most effective in enhancing self-care. Expert Patient Programmes (EPP) (DH, 2001), based on the concept of self-efficacy, might be most effective in achieving this aim.

Finally, from the literature review, it is recognised that there is limited evidence of improved clinical outcomes as a result of carrying out recommended self-care behaviours. The assertion of the AHA (Riegel et al, 2009a) that this evidence is needed as an urgent priority is echoed here as presently, there is some lack of evidence to support the recommendation of individual behaviours. Given this evidence, those specific self-care behaviours which improve clinical outcomes can be focused upon. Psychological interventions aimed at changing those illness and treatment beliefs which influence self-care can then be developed. Most importantly, the effect of such interventions on clinical outcomes could then be determined.

## **7.7 CONCLUSION**

In conclusion, this chapter has discussed the results of the study in relation to the literature and the CSM. The research design, namely mixed methods, has been discussed in terms of its strengths and dilemmas. Sampling strategies, data collection and analysis methods, employed in the two phases of the study have been evaluated and found to be effective in meeting the aims of the research. An analysis of the reliability and validity of the questionnaires reveals them to be both valid and reliable in this population, although it is acknowledged that the LAYHFQ, in particular, could be further developed. The use of the CSM is supported as the illness representation of consequences and treatment beliefs of medication knowledge and the impact of medication use on lifestyle were found to be significant predictors of self-care. Finally, the implications for nursing and healthcare practice have been considered. In particular, the development of interventions aimed at examining illness and treatment beliefs and correcting any misconceptions is recommended. The effectiveness of such interventions in enhancing self-care behaviour could then be evaluated in further research. Other opportunities for future research such as the exploration of illness coherence and medication knowledge have also been discussed. The following and final chapter brings the main points of the study together in an overall conclusion.

## **CHAPTER EIGHT: CONCLUSION**

This chapter concludes the thesis by first summarising the context of the study and restating the aims and methods. An overview of the main findings in relation to the aims, is presented. The use of a mixed methodology and the CSM, as discussed in the previous chapter, are evaluated. The implications for practice and suggestions for further research are summarised before reflecting on my personal development as a result of undertaking this work.

### **8.1 THE CONTEXT OF THE STUDY AND A REVIEW OF THE AIMS AND METHODS**

Heart failure is a significant clinical issue which has wide-ranging implications for patients and their families, the NHS and society as a whole. The financial cost of heart failure is high, accounting for 2% of the total NHS budget (NICE, 2010). There is a well-established evidence base for the medical diagnosis and treatment of heart failure which includes self-care - a key principle in the management of long-term conditions (DH, 2005a). Self-care in heart failure has been conceptualised as a decision-making process involving self-care maintenance behaviours such as adherence to medication and self-care management strategies such as managing symptoms (Dickson et al, 2006). Published literature describes a number of influencing factors on self-care including socio-demographic, healthcare system, illness and treatment-related factors. Personal beliefs are also expected to influence self-care behaviour, although few studies have previously addressed this. The CSM (Leventhal et al, 1980) has proved to be a useful framework for exploring illness beliefs and their relationship to health outcomes in other illnesses, and was selected as the theoretical framework for this study for this reason. Horne (1997) incorporated treatment beliefs into the CSM, which was also applied here.

The aims of the research were to explore illness representations, treatment beliefs and self-care in heart failure and to determine any relationships between these beliefs and behaviour.

In this study, a mixed methods approach was used (Creswell and Plano Clark, 2007), according to a pragmatic philosophical paradigm. The research was conducted in two sequential phases. Phase one was the collection and analysis of interview data exploring illness representations, treatment beliefs and self-care in a sample of twelve heart failure patients. These data were then used to adapt the IPQ-R (Moss-Morris et al, 2002) and the BMQ (Horne et al, 1999) in order to make them specific to a heart failure population. An



instrument measuring self-care was developed based on the EHFSBS (Jaarsma et al, 2003), using the interview data and the expert opinion of specialist HFNs. A socio-demographic questionnaire was also developed in order to describe the characteristics of the sample. Following a pilot study, these questionnaires were used in phase two - a cross-sectional survey of 169 patients with heart failure which described illness representations, treatment beliefs and self-care and enabled relationships between these variables to be determined, according to the main aim of the study.

## **8.2 SUMMARY OF THE FINDINGS**

The exploration of illness representations, treatment beliefs and self-care achieved through both qualitative and quantitative methods, revealed that heart failure was viewed as a long-term or chronic condition with serious consequences and associated with a high number of diverse and debilitating symptoms. This cluster of beliefs was related to negative emotions such as fear, anxiety and depression. The illness identity was problematic with patients finding it difficult to differentiate between heart failure and other cardiac conditions, which has implications for understanding the nature of the illness and its treatment. Many patients were unable to identify the cause of their heart failure although ageing and stress or worry were seen as the most likely causative agents. There was a prevalent belief that the illness could be controlled both personally and through the use of medication, with medication generally viewed as controlling the illness and its symptoms and personal control relating more to managing the emotional consequences of the living with heart failure. Although patients agreed that the illness made sense to them (coherence), this was generally not demonstrated in the interview sample in relation to other illness representations and subsequent behaviour.

There was a strong belief in the necessity of medication but this was balanced against some concerns, especially about side-effects and drug interactions. Although related to concerns, the concept of impact of medication use on lifestyle was developed which addressed the influence of medication use on practical, everyday life, for example, the disruptive influence of diuretics, difficulty in taking medication when going out and the need for frequent monitoring of the effects of medication. Perceived medication knowledge or the confidence in one's ability to understand the actions of medication and take it appropriately was also a developed theme and, like illness coherence, may be related to the concept of self-efficacy. In this sample, perceived medication knowledge was high and related to all other treatment beliefs. For some patients, medication use was socially influenced, with family members assisting in medication management. This was

influenced by gender with men reporting greater social influences. However, it was also found that this influence had a detrimental effect on perceived medication knowledge.

Self-care, including medication adherence was reportedly high although those behaviours most specific to heart failure such as taking a low salt diet and regular weighing were amongst the least commonly reported behaviours. It is hypothesised that, due to the lack of a clear illness identity, the purpose of carrying out these behaviours is similarly unclear. The reported high level of self-care may reflect the additional educational input and support expected as a result of the involvement of a specialist HFN, although a degree of social desirability cannot be ruled out. Managing symptoms and the emotional and social consequences of heart failure through resting, making an effort to keep a positive attitude and maintaining social networks, were also found to be important aspects of self-care as described by patients and suggested in the definition of self-care by the DH (2006a).

In addressing the main aim of the study, as predicted, a number of modest but statistically significant, correlations were found between beliefs and behaviour. The strongest correlations were found between self-care and medication knowledge and beliefs about the necessity of medication. Of illness representations, illness coherence was the most strongly correlating factor with self-care. Multiple regression analysis revealed that 46% of the variance in self-care could be explained by illness representations and treatment beliefs. Three factors were significant predictors of self-care - a belief in the illness having serious consequences, perceived medication knowledge and limited impact of medication use on lifestyle. Although not a specified aim of the research, no relationships were found between socio-demographic factors and self-care although it is acknowledged that there may have been insufficient variation in some characteristics in this sample to accurately determine such relationships.

The IPQ-R (HF), the MUHFQ and the LAYHFQ can be considered reliable and valid measures for use in a heart failure population. The IPQ-R (HF) required minimal adaptations from the IPQ-R and demonstrated good internal consistency ( $\alpha = 0.74$ ). The MUHFQ also demonstrated good internal consistency for all domains ( $\alpha > 0.70$ ), with the exception of the impact of medication use on lifestyle scale ( $\alpha = 0.56$ ). Therefore, conclusions drawn in relation to this domain are cautious. Factor analysis supported the 5-factor structure including the three additional domains developed from the interview data, adding support for the trustworthiness of the qualitative data. The LAYHFQ was more problematic since although the questionnaire as a whole was internally consistent ( $\alpha = 0.77$ ), most sub-scales failed to demonstrate sufficient reliability. As a result only relationships between beliefs and total self-care could be considered, which although

disappointing, is comparable to other published measures of self-care in heart failure such as the EHFSBS (Jaarsma, et al, 2003). This led to the conclusion that self-care might best be viewed as a list of individual behaviours rather than in terms of the theoretically derived constructs of self-care maintenance and self-care management behaviours.

### **8.3 SUMMARY OF THE CRITIQUE OF THE METHODOLOGY AND THE CSM**

A mixed methodology enabled a patient or lay perspective of beliefs and self-care to be incorporated into meaningful, illness-specific questionnaires. An integrated discussion of both the qualitative and quantitative results meant that the context and 'voices' of the participants could be retained. In this way a mixed methods approach was believed to 'add value' to the study in that it led to a better understanding of the topic than would have been achieved by using any single method. The main difficulty in using mixed methods lay in determining the relative strength of the findings where there were differences between the qualitative and quantitative results. Here, consideration was given to the most likely explanation for the findings.

In applying the CSM, some theoretical difficulties were apparent, especially in the qualitative data in categorising some responses. For example, depression could be considered a symptom in identity, a co-morbidity or an emotional response. Similarly, difficulty in walking may be both a symptom and a consequence of the illness. Perhaps most problematic was the concept of illness coherence which seemed to produce different results depending on the methodology used with the belief that the illness made sense being reported in the quantitative sample and a lack of illness coherence demonstrated in the qualitative phase. This was also apparent in other published studies (Cherrington et al, 2006; Voelmeck, 2006 and Horowitz et al, 2004). It is suggested that the term illness coherence may be being used differently according to the methodology. Similarly, in this study, a difference was found in the prevalence of negative emotions such as fear and depression, between the different samples with strong negative emotions apparent in the qualitative sample. This might be explained either as selection bias or suggests that interviews are a better method to uncover deep emotions compared to questionnaires.

In terms of treatment beliefs, the necessity-concerns framework (Horne et al, 1999) could be applied to this illness population. The impact of medication use on lifestyle was identified as a specific and practical concern about medication management. Two additional constructs of perceived medication knowledge and social influences on medication use were also identified and added to the overall concept of treatment beliefs.

There appears to be little empirical evidence to support the existence of the constructs of self-care maintenance and self-care management as described by Dickson et al (2006). Both the EHFSBS (Jaarsma et al, 2003) and the LAYHFQ suggest that patients view self-care as a number of separate behaviours, especially those relating to a general healthy lifestyle, such as reduced alcohol consumption and not smoking.

#### **8.4 IMPLICATIONS FOR PRACTICE AND SUGGESTIONS FOR FUTURE RESEARCH**

From these findings, a number of implications for practice are suggested. Targeted interventions particularly aimed at addressing those beliefs predictive of self-care should be developed. An example of such an intervention by Petrie et al (2002) focuses on advancing knowledge and exploring and correcting misconceptions. Such an approach seems feasible as many of the features of this type of consultation will be familiar to nurses working with heart failure patients. As perceived medication knowledge has been found to be a strong predictor of self-care, threats to that knowledge through, for example, changing the brand of medication and frequent changes to the medication regime should be avoided where possible. Additional educative support may be needed during the process of up-titration of medication. The impact of medication use on lifestyle should be recognised and explored and ways in which this impact might be reduced, for example, by altering the timing of medication such as diuretics, should be discussed and agreed with the patient.

In terms of suggestions for future research, further psychometric testing of the questionnaires might be carried out, for example to test for concurrent validity and external reliability. The impact of medication use on lifestyle should be further explored as this sub-scale demonstrated only moderate internal consistency in the MUHFQ. Although the LAYHFQ could be used clinically as a measure of total self-care, it is recommended that it is further developed so that each individual behaviour is assessed using a number of items which may enhance reliability. Further research is advocated on the concept of illness coherence, especially on the different ways in which this term seems to be being used. Similarly, the confidence in one's ability to understand the use of medication might be further explored, especially its relationship to the accuracy of medication knowledge. Finally, further evidence is needed in order to fully determine the effects of self-care behaviour on clinical outcomes (Riegel et al, for the AHA, 2009). Greater weight might then be added to the need for interventions aimed at changing illness and treatment beliefs which have been shown here to influence self-care.

## **8.5 PERSONAL REFLECTION**

The impetus for this study was to gain deeper understanding of the influence of beliefs on behaviour in patients with heart failure, which has, I think, been achieved. However, it has now led me to consider further questions, such as what influences the development of these beliefs? In undertaking this study, I have come to appreciate the complex jigsaw that is the relationship between beliefs and illness behaviour in a social context. In terms of the methodology, having been at first sceptical about the use of mixed methods ('mixed-up methods?'), I have come to firmly believe that the use of both qualitative and quantitative methods, when used critically, can lead to a much deeper understanding of the research question. For me personally, the use of statistical methods has been a steep learning curve, but I have now gained much greater confidence in the use of statistics in answering fundamental research questions. Finally, undertaking this research has been a privilege as I have been able to share, for a brief moment, the experience of patients who struggle every day with heart failure.

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